

Reflections on Being:

Spirituality within children's narrative.s of identity and disability

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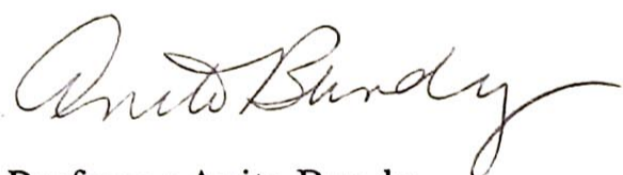
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A handwritten signature in black ink, appearing to read 'Imelda M. Burgman', with a long horizontal flourish extending to the right.

Date 15.2.06

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When you start on the road to Ithaca,
then pray that the road is long,
full of adventure, full of knowledge.
(Cavafy, 1959, p.36)

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Abstract

Spirituality supports our relations with others, our selves, and the world. Increasingly, occupational therapy research is considering the importance of spirituality within practice. While this research has investigated the place of spirituality within the lives of adults there has been no research focused on children with disabilities. The contribution of spirituality to the lives of children with disabilities and their experience of purpose, expression of choice, and the sustaining of a sense of self is unknown. The common experiences of vulnerability that children face in a disabling social world makes it important to investigate spirituality and resilience. This study foregrounds the relations between spirituality and the everyday construction of identity through experiences of resilience and vulnerability. The study explored the lived experience of spirituality for 18 children with disabilities utilising hermeneutic phenomenology and narrative conversation. The participants negotiated and expressed their identities through their roles as children, and children with disabilities, within the contexts of home, school and community. They spoke of themselves in relation to their impairment; its impact upon their daily lives and their sense of purpose, and how it affected their negotiation of relationships with others. They described experiences of resilience and vulnerability as they strived to express their desire for selfhood and sameness through the negotiation of conflicts, and their desire to belong and be accepted within their alterity of being. They also spoke of themselves as children who, like any other children, needed to negotiate their identities within societal and cultural boundaries. The heterogeneity of the participants' narratives illustrates the individual nature of the embodiment of spiritual qualities within everyday life, and the importance of spiritual qualities in

engagement in everyday occupations. This research contributes to new knowledge in occupational therapy theory and practice by considering other ways of understanding children with disabilities.

Chapter 1: Introduction

Spirituality is crucial to understanding the child and his or her occupational performance.

(Primeau & Ferguson, 1999, p. 470)

Why is spirituality important to children's occupational performance? Let me begin by telling you a story about two little boys.

On a cold autumn day in the Bronx, New York, at a preschool for children with special needs, surrounded by razor wire and nestled among the tenements, I met Jacob. He had severe cerebellar ataxia and was unable to speak, but his joy of being alive shone from his eyes and radiated from his smile. Jacob gave life everything he had. He was filled with determination; to be included, to be seen as capable and intelligent, and to be loved for himself. He fell and picked himself up again, literally and figuratively. He would not use any adaptive device he viewed as making him different from other children and was fierce in his suspicion and refusal of them. He built friendships with the children in his class, cared for them, and looked after their interests. He was adamant in his desire to experience everything life had to offer him, finding the courage, hope and trust he needed to survive in a world that was often harsh. Jacob was a child I believed would emotionally survive no matter what life cast his way. He had an inner strength of self that was beautiful to watch. I worked with Jacob for a year and he taught me so much about his way of being in the world.

A few years later, on a hot summer day in an Australian country town, I went on a day care visit to meet Ben. Ben was the same age as Jacob, had a severe developmental delay, and like Jacob he was unable to speak. Ben screamed for the hour of my visit. He found the world terrifying; screaming was his way of keeping the world

away, to be left alone. He was scared of new places, people (whether adults or children), toys, sounds, foods and textures. His only joy was when he was held by his mother or at home with his family, where he felt safe. The world he allowed himself to experience was very restricted and it was the way he wished it would stay. I spent the next two years with Ben, helping him to deal with his fears and to find pleasure in life outside the confines he had erected and those erected for him by society.

The stories of these two children resonate with the stories of many children I have worked with over the years. With children like Jacob, what helps them to sustain their resilience, continuing their engagement in occupational roles? For children like Ben, what can help them to lessen their vulnerability and facilitate their occupational engagement? From these initial questions, my interest in the embodiment of spirituality took shape.

Occupational therapy's focus on the medical and psychological knowledge of children did not meet my desire for a deeper understanding of children's being. My prescriptive understandings of children often positioned them within restrictive models of intervention, where their desires for themselves were secondary to my professional goals of developmental task achievement. These understandings were not sufficient to enable me to engage respectfully with children like Jacob and Ben. With both of these children I needed to re-evaluate my professional direction if I wanted to meet their desires and facilitate their engagement in all aspects of their lives. I needed to consider other ways of understanding children beyond that of a 'clinical diagnosis'.

The cultural re-emergence of spirituality as an important dimension in daily life and its significance in the lives of adults (Borysenko, 1990; Moore, 1992) led me to

search for texts speaking of spirituality in the lives of children. Perhaps there I would find an understanding of the relationship of spirituality to resilience and engagement. While little had been written, the narratives of children from diverse backgrounds presented by Coles (1990) provided a foundation from which to consider spirituality in the lives of children. Turning to current understandings of spirituality within occupational therapy provided a general thread to follow in exploring its potential significance in the lives of children like Jacob and Ben. In this research I wished to listen attentively and thoughtfully to children with disabilities, to start to unravel what it means to be able to draw on spiritual qualities that may help to sustain resilience and engagement within their life experiences.

The importance of spirituality to physical and emotional well-being has been explored in the fields of medicine, psychiatry and psychology (Carlson & Shield, 1989; Goleman, 1997; Miller & Thoresen, 1999; Wright & Sayre Adams, 2000). The spiritual care of children with life threatening or chronic illnesses (Fulton & Moore, 1995; Hart & Schneider, 1997) and the spiritual needs of those who are dying (Kubler-Ross, 1969, 1975, 1981) have been explored within the areas of nursing and psychiatry. Exploring the needs and care of children has highlighted the common themes of spirituality experienced by children with diverse life experiences. However, researchers have not addressed spirituality in the lives of children with disabilities. How children with disabilities utilise spirituality within their everyday lives remains unanswered.

The primary focus of occupational therapy intervention for children with disabilities is to assist them in the development of their occupational performance roles, and the tasks within those roles (Case-Smith, Allen & Pratt, 1996). Within this focus is

the enhancement of children's abilities to adapt, grow and change in harmony with their physical/sensory (Gilfoyle, Grady & Moore, 1990) cognitive (Piaget, 1955) and emotional development (Erikson, 1963). The core component of spirituality in the lives of children may be a primary enabler for successful adaptation to the challenges in their lives. Their ability to utilise spiritual qualities including hope, courage and trust may impact on their ability to maximise their potential in all aspects of their lives, as it may for children without disabilities.

The importance of the relationship between occupational therapists and children is in its ability to support therapeutic change in children's lives (Mosey, 1986). In this relationship, the influence of occupational therapists in facilitating children's use of their physical, cognitive and emotional resources for occupational engagement is bound to our abilities to understand the inner resources children have available to them (Van Amburg, 1997). Our understanding, and therefore application, of this relationship with children is currently focused on children's social and emotional needs and resources (O'Brien, 1996; Saunders, Sayer & Goodale, 1999). The knowledge base of the profession does not include an understanding of children's spirituality to enable therapists to utilise this rich and powerful aspect of children's lives within the therapeutic relationship. Therefore, we may not have the ability to assist children to develop this aspect of themselves as a means of enablement within their lives.

The occupational performance of children with disabilities is affected not only by their physical, sensory or cognitive impairment, but also by their response to the social construction of their 'disability'. Children's beliefs and values about themselves and the world in which they live shape these responses (Merleau-Ponty, 1964). That

these beliefs are shaped by children's close relationships and responses from others is strongly argued by Bronfenbrenner (1979) and disabilities studies scholars (e.g., Morris, 1991; Shakespeare, 1996). However, children also influence their world (Bronfenbrenner & Morris, 1998). How children with disabilities define their sense of agency, purpose and their concept of self through their relations with others are important questions to be answered.

Phenomenology contributes an understanding to these questions. The entwined nature of the self with its experience of the world has been explored by Merleau-Ponty (1962) in relation to perception and the embodiment of the self. The self can only be known through its ways of being expressed in relation to the world. Phenomenology views children as active and relational beings (Merleau-Ponty, 1964). In contrast to developmental models where children are positioned within a stage of becoming (into adulthood), phenomenology enfolds becoming within being. Children's identities are fluid and relational, where being encompasses a changing and developing identity. This thesis builds upon this phenomenological view of being within children's identities.

The uniqueness of each child is expressed through his or her lived experience, where experiences shape children's knowing of their individual and social identities. This lived experience is also entwined with children's history, present and future. Thus, children are being and becoming at each moment in their lives, an experience not limited to adults nor bound by traditional theories and understandings of childhood. The experiencing of relationships is unique to each child and can only be understood within a view of the self as separate from but connected to others. The multidimensional nature of each child's identity and interactions with the world asks us to consider children as

intentional beings with complex inner lives. We must also consider spirituality's contribution to children's sense of self and interactions with others.

Two occupational therapy models explicitly acknowledging the presence of spirituality have emerged in the past 10 years (Canadian Association of Occupational Therapists, 1997; Chapparo & Ranka, 1996). In these models views of self are considered within particular dimensions, for example, cognitive and physical. However, there is limited guidance concerning the relational nature of spirituality and how identity is constructed through being in the world. Understandings of spirituality are often focused on self-conscious 'meaning' as constituted through religious perspectives, rather than embodied understandings. Through exploring the embodiment of spirituality, this thesis offers a unique analysis of spiritual relations within the everyday lives of children with disabilities. This focus offers a conceptualisation of spirituality that contributes to the broader understandings of spirituality embedded within occupational therapy models.

How spirituality supports adults with disabilities to experience purpose and seek engagement in their lives are very important questions for the occupational therapy profession. Occupational therapists have responded by beginning to attend to these questions (e.g., Clark, 1993; Howard & Howard, 1997; Kroeker, 1997; Neuhaus, 1997; Peloquin, 1997). These same questions are important when considering children with disabilities.

Children's ways of knowing the spiritual dimension, as distinct from the religious expression of spirituality, has implications for occupational therapy theory and practice. In order to facilitate change in the lives of children with disabilities, we need to

remain cognisant of the impact of children's spirituality in relation to their ability to achieve in a way that is meaningful for them (Moustakas, 1959). In order for us to gain insight into the spiritual beliefs and values held by children in relation to their impairment and its impact on their lives, it is important to understand the stories of their lives (Clark, 1993). The absent voices of children with disabilities led to my growing awareness of the need to engage with their stories.

This research addressed the concept of spirituality in the lives of children with disabilities for the purpose of developing the knowledge base of this area as a core component in paediatric occupational therapy practice. The overarching research question asked; how do children with disabilities embody spiritual qualities in their everyday lives? Within this central question were the more specific questions of: how do children with disabilities experience purpose, and therefore meaning, in their everyday lives?; how do they utilise spiritual qualities to sustain and develop their sense of self within their world?; and how do they utilise spiritual qualities to determine and express their choices and engagement in occupational roles? Answering these questions involved the phenomenological exploration of the lifeworld of children with disabilities and how these children utilised spiritual qualities to assist them in the engagement with, and performance of their occupational roles.

Knowing how children with disabilities respond to everyday life situations from a spiritual perspective will assist us to connect with children in ways that are meaningful for children. Through this research, knowledge of the ways in which children with disabilities utilise spirituality in their daily lives, its influence and outcomes, is enhanced. This knowledge can then be incorporated by us into the therapeutic

relationship in ways that enhance the quality and responsive nature of that relationship. This research made a unique contribution to occupational science through its focus on the construction of identity and the lived experience of spirituality in relation to children and disability. Finally, occupational therapy's unique perspective on the everyday is well suited to engaging in and offering this study to other professions.

Thesis Structure

Because of their influence on occupational therapy theory and practice, key theoretical constructions of childhood and disability are examined in Chapter 2. The reader is asked to consider the professional gaze constructed through theories and models, and to further consider what a different gaze might reveal. How children construct their sense of self, through their perceptions and the perceptions of significant others, explores the personal and social construction of identity.

The embodiment of spirituality is explored in Chapter 3. This chapter discusses the positioning of spirituality within occupational therapy models, literature and research. Current understandings of children's spirituality are identified, which like understandings of children's identities are often positioned within developmental frameworks. Exploration of the embodied nature of spirituality through a discussion of spiritual qualities establishes the conceptual framework of the research.

The 18 children who participated in the research are introduced in Chapter 4. I describe the application of the hermeneutic phenomenological methodology (van Manen, 1990) and narrative conversations method (Ricoeur, 1992; Riessman, 2002) employed for inquiry and analysis. The interview process is presented in detail, from the initial meeting to post interview contact.

The structure of the thesis diverges from the traditional from Chapter 5 onwards. Rather than the concluding chapter containing the detailed discussion of the research findings and their implications, I have chosen include these discussions in Chapters 5 through 8.

The combined analysis and discussion of the key themes to emerge from the research are presented in Chapters 5 through 8. Each chapter considers the children's narratives within a different context; self, home, school and community, in keeping with Bronfenbrenner's (1979) ecological theory. In each of these chapters the children's narratives are substantial. My interpretations stand with their original dialogues to retain and respect the diversity of their voices.

Chapter 5 focuses on how the children speak of themselves. Through stories of origin, perceptions of their impairment and beliefs about their qualities they narrate their understandings of being. Through their stories of otherness and desires for becoming they express their wishes for themselves. Chapter 6 explores the children's perceptions of family relationships and the roles they play. The children speak of negotiating their identities within family relationships, and how they experience belonging or disconnection. Chapter 7 discusses the children's related school experiences of policy, learning, and relationships with teachers, peers and friends. The importance of relationships and sources of purpose are woven into their narratives. In Chapter 8 the children speak of their experiences within other communities. These communities include leisure forums, medical and disability services, and religious faiths. The children also speak of their world consciousness and their desires for respect from others.

At the end of Chapters 2 through 8 I have made connections between the discussion and/or analysis and occupational therapy practice. The final threads of the thesis are drawn together in Chapter 9, through reflection on theoretical knowledge, listening to the children's voices, and their narratives. This chapter concludes with the methodological limitations of the study and recommendations for further research.

Terms of Reference

I refer to the participants in this research as children, rather than children with disabilities. As I wish to recognise the multiplicity of children I have chosen not to categorise the participants on the basis of disability as it is categorised within a normal/abnormal hierarchy of being. This is not to deny their impairment rather it is to foreground their experiences as children. There are occasions when I do not apply this preferred terminology, where a particular point requires the difference to be noted.

When discussing occupational therapy knowledge and practice, I have chosen to position myself within this group rather than as an outsider. Therefore, I have used the inclusive terms 'us', 'we' and 'our'.

Chapter 2: Constructing Identity

Any account of what it might mean to be a child must be situated against the backdrop of the particular ways in which cultural conceptions of age and status are intertwined and embedded in the particular structural arrangements of a society.

(James, Jenks & Prout, 1998, p. 63)

Considering how key constructions of childhood influence occupational therapy perspectives of children, and how they influence children's perspectives of themselves, makes explicit the significant theoretical expectations placed on children's lives. Influences arising from deeply held theory are felt in children's expression of the self and in the construction of their identities.

Developmental theories and models of disability inform our current perspectives of children. Our perspective does not foreground children's knowing of themselves; neither does it facilitate them to be the makers or speakers of their own identities. Viewing childhood as a developmental process rather than a way of being (Merleau-Ponty, 1964) is reflected in the relationships we establish with children (Fattore & Turnbull, 2000; James et al., 1998; Mason, 2000; Prout, 2001). Children's knowing of themselves is constrained through theoretical expectations of their behaviour, potentially marginalising them within the therapeutic relationship.

In contrast, strong voices over the decades have presented views characterising the experience of childhood as a time of agency rather than one of response to adult perceptions of children's place and roles within society (e.g., Bronfenbrenner, 1979; Maslow, 1999; Moustakas, 1973). There is a growing body of sociological research presenting the experiences of childhood in this light (e.g., Davies, 2000; Hockey & James, 2003; Prout, 2001). This research also highlights the impact of cultural and social

influences on children's ability to express their identities and to engage with societal expectations.

Social constructions of childhood enable a reflective consideration of the positioning of children with disabilities, and how this may influence our understandings of their ways of being in the world. Views of childhood as a time of agency, challenge our adult perceptions and invite us to consider children as being; who they are, how they choose to engage with the world, and how they choose to become, where negotiating being involves choice. As reflective practitioners we need to consider the ways in which these views challenge and reinform widely-held perceptions of childhood, and thus our understandings of and relations with children.

Alternative understandings view each child as a unique being, who brings to his or her development a unique set of characteristics, hopes and fears. Each child also encounters a unique set of experiences that are socially and historically specific, which influence his or her understanding of and response to his or her world. These experiences cannot be understood if, as occupational therapists, we restrict ourselves to traditional understandings of stages of development.

Reconsidering Identity

Health and educational policies, founded on developmental theory, reinforce the construction of identity through developmental achievement and social aptitude. Rather than being a unique expression of the self in relation to the world, health and educational practices position identity within a skill based framework, privileging conformity over diversity. When viewed through the lens of developmental theorists (Piaget, 1932, 1955, 1962; Erikson, 1963; Freud, 1933; Kohlberg, 1964), children are expected to conform to

hierarchical markers in their development. As a result of these theories, children are relegated to a responsive rather than initiatory and creative role in their own lives (D'Alessio, 1990; James et al., 1998). The ensuing homogeneity of childhood maintains adult power through the control of the expectations of children (Foucault, 1973, 1977). The 'otherness' of children is thus reinforced and internalised through adult acceptance of developmental mores.

Identity is theoretically viewed as a socially constructed self-concept, rather than constructed in relation with others and through the understandings of the self. This theoretical concept is particularly limiting because it assumes that children who are not able to master specific, socially valued tasks are unable to develop a positive sense of self. Independence and capability measured through the achievement of proscribed developmental tasks (Havighurst, 1972) leaves many children with experiences of inferiority and defeat.

However, the ability for children to succeed and know themselves as agentic can be dramatically reconstructed if independence and capability are viewed from alternative perspectives that enable children to determine and engage with their own challenges. A sociological and phenomenological concept of self encompasses embodiment and agency where there is a complex notion of interiority¹. From this perspective, mastery is not seen as merely the ability to produce "things" (Erikson, 1963 p.259), but as the ability of children to share their time and space, and their abilities to care for and respect others and themselves. Mastery would also involve children's

¹ The inner and psychological life of the self.

abilities to meet the challenges in their lives, including the ways they strive to express their identities.

The quest for identity is a fundamental part of children's lives (Moustakas, 1959). Identity is a construction of the self in the world, rather than something 'given' by the world (Giddens, 1991). There is an intrinsic drive moving children towards growth, which comes from their desire to learn and to develop their abilities, and from the encouragement they receive (Maslow, 1999; Rogers, 1951). Children's ongoing motivation is the wish to develop themselves to their full potential, in all aspects of their life, to sustain and develop their sense of self and self purpose (Maslow, 1970).

The environment, significant others, and repetitions of experiences over time contribute to the formation of identity. These components within children's worlds may either encourage or discourage personal expression and contribute to knowing the self within the world (Bronfenbrenner & Morris, 1998). The 'biopsychological' resources of the self and the demands the self makes upon the world contribute to the construction of identity. Thus, the development of identity and the development of a sense of agency are within the interactive process of the self and the world. Children influence and are influenced by their family, peers, teachers, and others in their life (Bandura, 1986; Bronfenbrenner, 1979; Bronfenbrenner & Morris). The degrees of influence each has on the other will, in part, depend on the effect of these interactions on children's sense of self.

Positive interactions with others enhance the development of self. Conversely, negative interactions restrict the development of self (Bronfenbrenner & Morris, 1998). Parental attitudes, no matter how subtle, influence children's development of self.

Children who have been treated by their parents as having intrinsic worth express themselves freely, conveying their thoughts and feelings, seeing themselves as having agency and self worth, maximising their potential for growth and change (Bettelheim, 1987; Moustakas, 1959; Rogers, 1951). Parental influences, which give the message to children that they are not valued cause children to doubt themselves, to lose trust in themselves (Moustakas; Rogers, 1961). This can cause children to doubt their agency and in turn diminish their potential for growth. They may place their sense of knowing themselves in others, rather than in themselves (Moustakas). This perception of others knowing their worth may then be transferred to the world of the school, where teachers relegate children to a hierarchical position based on their conformity and achievement (James et al., 1998).

Children will try to maintain their sense of self through whatever means possible (Moustakas, 1959). Children may create a socially acceptable identity, which overshadows the self and meets the expectations of others (Maslow, 1999; Weeber, 1999; Winnicott, 1965). This identity is then continually dependent on the responses that children receive. The stability of this identity is ultimately fragile.

Even though children may relegate to their 'shadow self' (Jung, 1933; Zweig & Wolf, 1977) those parts of themselves others have responded to negatively, they will continue to try to express those qualities, perhaps through play, artistic expression, or antisocial behaviour (Moustakas, 1959; Rogers, 1961; Slade, 1954). All of these are ways in which children are trying to make themselves and their feelings heard. The development of an identity accepted by others may cause children to engage in

behaviours that come at a price to the self, even though they provide an immediate strengthening of the perception of the self as agentic.

Children's feelings of control over their experiences influence the development of self (Rogers, 1951). Their awareness of self will be reduced if they have ceded this control to their parents, teachers, therapists, siblings or peers (Maslow, 1999). Children can discover who they are, rather than the self others expect them to be (Rogers, 1961) by allowing this self to emerge (Moustakas, 1973), which we can facilitate within the therapeutic relationship. Rogers (1961) believed that with this emergence comes the realisation of responsibility for the self. Children gain a perception of all they can be and it places agency and control within children's selves rather than with others.

Enfolded with children's desires for self-expression and agency is the desire to belong. Children's desires for selfhood and sameness (Ricoeur, 1992) create a foundation for the expression of individual identities within lived experiences. Selfhood is the expression of individual identity through personal characteristics. Children express their identities through their likes and dislikes, hopes and dreams, ways of seeing the world and ways of responding to the world. Selfhood is formed through their social relations with family, peers and society. Children's identities are created within the understandings and boundaries of society and culture.

Sameness of identity does not equate to 'normality', which in turn implies an exclusion of difference. Rather it is a process of identification with others through the recognition of common aspects of self and human identity (Ricoeur, 1992). The experience of being a boy or girl, child, sibling, friend, peer, school student, neighbour and citizen, is a sameness based on a commonality of diversity. There is an enfoldment

with others through connections of family, school and community, with a recognition of the fluid and relational nature of identity.

The childhood experience is not homogeneous (Cattanach, 1997; James & Prout, 1990; Prout, 2001). I take the position that the childhood experience of impairment and disability is similarly unique. To take Bronfenbrenner's (1979) initial thinking further, the contribution of spirituality to the construction of identity needs to be considered. The self's resources are not confined to the physical, psychological and intellectual; they include spirituality, which contributes an additional knowledge of being in the world (Coles, 1990; Hart, 2003).

Identity and Disability

Sociological literature makes an important, but general contribution to occupational therapists' understandings of the construction of identity for children with disabilities. Disability literature has begun to explore the views of children with disabilities (e.g., Connors & Stalker, 2003; Shevlin, Kenny & McNeela, 2002). However, the constructions of identity for children with disabilities remain largely based on knowledge of the experiences of adults with disabilities (e.g., Robinson & Stalker, 1998). The ecological theory of development (Bronfenbrenner 1979) provides a means of contextualising the constructions of the experience of impairment and disability. Children's experiences of self (physical, cognitive and emotional) and those experienced through society (cultural and sociological) can begin to be acknowledged.

Bronfenbrenner's (1979) ecological theory illuminates the social construction of children's sense of self as children with disabilities. The characteristics that label children with disabilities place them within a specific position and role in society.

Children's interactions with society reinforce the perceptions of children as a result of this positioning and role. The repetition of devaluing or other valuing for such children, which occurs in their daily interactions and is repeated over time, reinforces the perception that they have an 'otherness' of being, which is not valued. The reinforcement of this difficulty of difference comes from others, such as peers, teachers, the community, the health sector and from an environment that does not adequately enable the living out of their identities (Aptekar, 1986).

For children with disabilities, ecological issues including health and educational policies and their related bodies of knowledge, perceptions of family members, school communities and peers shape the construction of social identity. Children's responses to these issues and their manifestation in their everyday lives in turn influence the impact they have on their sense of self and on society as a whole. Children's knowing of themselves and their way of being within the world also influences the warp and weft of their own lives and ultimately that of the societal fabric (D'Alessio, 1990; Merleau-Ponty, 1964; Prout, 2001; Smith, 2000).

The construction of the medical and social models of disability has shaped the way in which children with disabilities are culturally represented within society (Mitchell & Snyder, 1997; Wendell, 1997) and consequently within occupational therapy practice. Bodies of knowledge within the health arena that determine the level and types of knowledge that children have access to in relation to their bodies, support the adult power of knowing the childhood experience (Foucault, 1973). Health professionals then enact this knowledge and determine the choices that children are deemed capable of making (Alderson, 1993; Closs, 1998).

The medical/health culture reinforces the perspective of children with disabilities as being in need of help, which assumes a 'helplessness' and incompleteness on the part of children (Billington, Hockey & Strawbridge, 1998; Shaw, 1998; Zola, 1993). To receive sympathy and support from professionals children are expected to enact this role (Frank, 1995; Shakespeare, 1996). The maintenance of children's identities, as incomplete without the intervention of an adult, sustains the identities of health professionals (Becker, 1992).

The medical model's reductionist view of impairment as a condition to be corrected and controlled, rather than as a way of being, has led to the perception of children with disabilities as 'suffering' and to be pitied as victims of circumstance (Mitchell & Snyder, 1997; Swain & French, 2000). This model denies the social subjugation experienced by children with disabilities and how this subjugation reinforces the medical model's focus on 'saving' children from themselves (Prout, 2000; Zola, 1993). The lived experience and the understanding of that experience (Lupton, 1997) by children with disabilities is also largely ignored, because of a continued focus on the use of traditional taxonomies as measures of meaning (Gordon & Rosenblum, 2001; Tyler, 1997; Williams, 1996). Consequently there is a presupposed homogeneity between children with disabilities, which disregards their experiences and their individuality of self (Billington et al., 1998; James et al., 1998).

The social model of disability addresses the construction of disability enforced on people with disabilities through societal limitations and responses (Gleeson, 1995). This model highlights the assumed 'normality' inherent within social constructions of impairment as disability (Shakespeare, 1996). Within society, disability is often

positioned as other, and lesser, in relation to 'normality', as defined through binary oppositions. This assumption affects the societal positioning of people with disabilities through perceptions that devalue the integrity of their alterity of being. Alterity (Merleau-Ponty, 1968) is an 'absolute otherness' of self that escapes these representational systems of culture. A different, but as valuable, way of being is experienced in relation to another. Thus, children with disabilities have an alterity of being in relation to children without disabilities that has been defined as lesser through cultural representations.

However, the social model of disability does not address the impairments of "pain and chronic illness" (Swain & French, 2000, p. 571) that can be part of the lived experience of an impairment. In addition, it does not sufficiently address the individual lived experience of *children* with disabilities. Children choose how they live with and respond to their impairment and its impact on their life (Alderson, 1993; Corker & French, 1999). Children with disabilities have an alterity of being in relation to adults with disabilities, which is yet to be adequately addressed by the social model of disability. The limited knowledge of children's views and experiences leaves an absence of understanding of the impact on children's identities by social structures and their interpretation in the relations of daily life.

The limitations and powerlessness children experience relates not only to their child status but also to their disability. Through health and educational practices, children with disabilities who are unable to meet the developmental markers of 'normality' are positioned on the fringes of society (James et al., 1998). Adults are gatekeepers for acceptance and inclusion in the world. They reinforce the need to

conform. Adult 'habits of perception' (Merleau-Ponty, 1962) limit the expectation of developmental change and growth, leaving children to either accept their role or to challenge it and potentially be discounted or further marginalised. Objective measures rather than subjective understandings of children's alterity reinforce the 'otherness' of children with disabilities (Merleau-Ponty, 1968; Wendell, 1997).

Within educational settings children as a cultural group are allowed token power (Williams & Bendelow, 1998). The markers and rights to transition and access to knowledge for learning achievement contribute to children's "educational identity" (James et al., 1998, p. 42). Although the educational segregation of children with disabilities continues to occur (Gordon & Rosenblum, 2001; Priestley, 1999; Shakespeare, 1996; Shaw, 1998), educational policies are slowly moving towards the inclusion of children with disabilities into mainstream schools. However, this is more through providing environmental access and adult support systems than addressing societal attitudes that create psychological barriers for children (Priestley).

Devaluing societal attitudes perpetuate subtle physical barriers such as access to curriculum and appropriate learning tools (Baker & Donnelly, 2001; Gleeson, 1995). In addition, adults and peers enact societal attitudes in the classroom and the playground. Children with disabilities may remain dependent on the 'benevolence' of adults for the provision of emotional and sometimes physical safety. The power within this relationship remains firmly within the adult's grasp, with children expected to remain quiescent and grateful (Morris, 1991).

The reinforcement of these perceptions of self includes the marginalisation of people with disabilities by general culture (Morris, 1991; Shakespeare, 1996) through

scientific reconstruction and social devaluing. The effects of marginalisation and the response of children with disabilities to this positioning, either through rejection or acceptance of the perception, highlights the emotional content of these perceptions. The necessity for children to live within a world where they are bound by roles that are predetermined, where senses of belonging are conditional, leads to a dissonance between identity and self (Musschenga, 2000).

Within their everyday worlds, children construct their knowing of themselves as 'children', and as children with disabilities within families, friendships and society (Billington et al., 1998; Prout, 2000). The uniqueness of their lives and knowing of themselves are silent voices within both the medical and social constructions of disability (James et al., 1998; Shakespeare, 1996; Wendell, 1997). These constructions also point to the ways in which children may subsequently feel about themselves, as powerless, not valued, needing to be 'fixed', a dependent minority (Wendell). Within this, individuals are an isolated minority of one (Billington et al.; Morris, 1991). As a result, it is not surprising if a child with a 'disability' expresses a wish to 'be normal', to take up normalised discourses that value identity in terms of a denial of diversity.

A perception of self that comes only from the external is potentially life limiting for children's sense of agency. If, however, children's sense of self also comes from within, from their spirituality, then there may be a richness to be explored and a strength to be found despite the voices of society. Knowing of, and drawing on, spiritual qualities may quieten the voices of society, providing a response so they do not drown out the unique, multiple dimensions of self. This thesis will explore the idea that spirituality is

the space of interiority through which children can negotiate and challenge social constructions.

Let us take Bronfenbrenner's (1979) ecological theory one step further into children's internal worlds, and consider that children's spirituality influences their cognitive and emotional responses, and is in turn influenced by these responses. Thus, the expression of self becomes a deeper circle with children's spirituality at its centre. Spirituality influences the development of identity, as identity influences spirituality. Here we can find an interweaving of the self with the world (Merleau-Ponty, 1962) that acknowledges the spiritual dimension of self. Children cannot be separated from their worlds. Each is in the other as each influences the other (Barrett-Lennard, 1998; Becker, 1992; Bronfenbrenner & Morris, 1998).

Children's reflection on being and on being in the world develops consciousness through the suspension of preconceived notions, creating space for alternative understandings to appear. Reflection may occur through a brief stepping back from the world, as in a child's space behind a curtain (Langeveld, 1983) (a quiet space that is within but without) or may occur within the pace of life where children choose to reflect while immersed in their experiences (Matthews, 1983). Here the subjective and objective are, as always, intertwined (Merleau-Ponty, 1962).

This thesis seeks to phenomenologically explore the lived experience of identity and disability. How do children with disabilities negotiate selfhood in relation with others? How do they then know identity and seek to express it within the world? How do they resolve the incongruity between the different aspects of self? How do they resolve their need for sameness? These questions seek to understand the interrelatedness

of children and their world (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 1998), the relatedness within which children's voices (identities) are heard (Fattore & Turnbull, 2000; Prout, 2001).

A phenomenological approach can explore how children negotiate the complexities of everyday life. This approach views the relations of self and the self-with-others as embodied within the world; there is an intimate connection between children and the world (Merleau-Ponty, 1962). If we consider children's connection with others then we are considering the importance of family, friends and significant others in their life. Connection aids resiliency to life's challenges and enables children to respond, knowing others support their efforts. The positive responses of others influence how children perceive themselves and their ability to negotiate life (Garbarino & Scott, 1989). The coping, or non-coping, strategies of those around them also influence children (Bronfenbrenner, 1979; Gore & Eckenrode, 1996; Maslow, 1970). Affective experiences and influences impact on children's understandings of their identity, selfhood and sameness (Ricoeur, 1992). The ability to take risks and to have the support of parents or others to engage in life is essential to children's development of self (Bettelheim, 1987; Bronfenbrenner & Morris, 1998).

Adult influences. Parental influences shape children's early social development. Children initially internalise parental beliefs and attitudes (Bandura, 1986; Bronfenbrenner, 1979; Pellegrini & Bjorklund, 1998). Cultural, social and familial environments shape parents' responses, thus society's mores influence children (James & Prout, 1990; Minuchin, 1974; Neven, 1996). The cultural context of development influences children's specific view of the self, which includes gender roles and

expectations (Bandura; Miller & Bersoff, 1995). However, children do not simply accept cultural practices associated with lived experience, but interpret these practices within their knowing of themselves and others (Coles, 1986, 1990).

Cultural responses to children's impairments impact upon the struggle of families for acceptance and support within society (Thomas, 1998). The family may experience ostracism at one extreme, and dependence at another extreme. Parents must also conform to societal rules in order for their children to receive health and educational services (Cohen, 1999). They are expected to join with their children in being 'grateful' for what is granted. Service providers may label parents as 'difficult' if they are vocal in their concern over the quality or frequency of services for their children (Clear, 1999). The responses parents and children receive from service providers influence children's perceptions of their 'right' to express themselves.

Within the family circle children may or may not be allowed to express their identities. Societal and cultural mores influence children's place within the family, the roles they are expected to fulfil (Billington et al., 1998; Bronfenbrenner & Morris, 1998; Minuchin, 1974; Prout, 2001) and consequently the power they are accorded. Children with disabilities may experience additional expectations. Family knowledge and attitudes towards a child's impairment and their subsequent expectations of a child's development and self-agency influence a child's expression of self and formation of identity (Swain & French, 2000; Thomas, 1998). Adults and older siblings or cousins, or younger and more physically or intellectually adept siblings may confer or retain power, rather than agency being placed within and expressed from children's knowing of themselves.

Parental support for children's development of self is central to children developing a strong sense of self, which encompasses a positive identity (Bettelheim, 1987; Rogers, 1951). The influence of siblings, teachers, peers, and significant others in children's lives also create for children an external picture of themselves that may not accurately reflect children's unique selves. When children's environments do not support their physical, emotional, cognitive or social needs, then children become vulnerable to developing a sense of self that is fragile and dependent upon others (Bettelheim; Maslow, 1999).

Often, children with disabilities grow up in a family where they are the only person who has an impairment, creating an accompanying sense of isolation through difference (Morris, 1991; Shakespeare, 1996; Weeber, 1999; Zola, 1993). Role models for exercising agency within relationships are not usually other people with disabilities (Shakespeare, 1996). Adults with disabilities often only enter the world of children as occasional figures on TV or as similar (powerless) children in schools, health or social systems. These contexts do not generally support the expression of agency (Brown & Cohen, 1996). Elite athletes with disabilities may provide agentic role models for children, but they also reinforce the need to become more than what one is in order to achieve conditional acceptance in the wider society (Shakespeare). When athletes with disabilities are forced to compete at segregated events with less public exposure and recognition this conditional acceptance is exacerbated. Where does this leave the sense of agency for children whose impairment precludes them from achieving physical prowess? (Wendell, 1997).

Intellectual role models for children with disabilities are not highly visible, they are 'hidden' in universities (Mitchell & Snyder, 1997), as authors of discourses to which children are unlikely to have access. They are rarely school teachers, doctors, nurses, therapists or other adults that pervade the daily life of children with disabilities. Relations between people without impairments, whether adults or children, often provides the basis for children's modelling of the effective use of power within relationships, both intimate and societal. This may provide some essential skills but it does not enable children to negotiate and sustain their sense of agency when interactions are coloured by societal attitudes. They are not encouraged to express their uniqueness and develop their potential.

Siblings and peers. Initially, parents and family meet children's need to belong (Maslow, 1970). Sibling relationships provide important avenues for negotiating the self through independence, dependence and interdependence (Hockey & James, 2003). Children's learning within these relationships is foundational to their understandings of relationships with peers (Minuchin, 1974; Neven, 1996). Peer acceptance and acceptance by adults outside of the family circle (e.g., teachers) provide further contexts for the experience of belonging.

Sibling relationships are sources of company and conflict (Brannen, Heptinstall & Bhopal, 2000; Minuchin, 1974). Children within families may help and support each other in practical and emotional ways, for example, older siblings may teach and care for younger siblings. Siblings may band together in negotiating difficult parental relationships of abuse and neglect. Siblings also fight with each other. These fights may occur over privacy, respect, and boundaries of emotional and physical sharing. The

ambivalence within sibling relationships is well documented in the literature (Brannen et al.).

Research literature has focused on the demands children with disabilities place on the sibling relationship (Banks et al., 2001; Fleitas, 2000). Siblings have been found to experience stress, depression and isolation from peers. However, they may also experience increased self-esteem, resilience and empathy (Stainton & Besser, 1998; Turnbull & Turnbull, 2001). For children with disabilities, ongoing dependency needs may impact upon sibling relationships. Through providing support and relief for parents, their siblings may be placed in the role of carer (Banks et al.). Children with disabilities may experience emotional rejection and isolation from sibling play through perceptions of difference rather than sameness (Fleitas). There may also be feelings of jealousy as the child with an impairment appears to receive more attention from a parent (Banks et al.).

Siblings may enact adult perceptions of the abilities and value of children with disabilities (Turnbull & Turnbull, 2001). For children with disabilities there may be an expectation of remaining within a dependent role. Within this role there is a limitation of expression of the multidimensional aspects of the self. Children's identities may become bound to the expectations of others in order to belong. If children then carry this role into their peer interactions they will continue to be unable to develop a sense of self separate from the expectations of others (Minuchin, 1974).

The peer groups of middle childhood provide a sense of belonging and a need for peer approval in order to remain a part of the group (Davies, 2000). Peer groups provide a further means for children to practice social skills, required in wider society: sharing,

negotiating, compromising, working together for shared goals. However, adults oversee and may directly control peer relationships in the school playground. Adult control contributes to the social construction of friendships based on adult understandings rather than the needs of children (James et al., 1998).

As in family relationships, the responses of other children towards children with disabilities reflect adult attitudes (Closs, 1998; Priestley, 1999; Priestley, Corker & Watson, 1999; Zola, 1993). Children may be forced to remain socially and emotionally isolated from their peers, being 'helped' or avoided due to their perceived difference (Baker & Donnelly, 2001; Davies, 2000; Hurley-Geffner, 1995; Prout, 2000). Children who are 'helped' may be placed in a dependent role by their peers. They may choose to remain in this role for fear of losing the friendship, requiring a denial of the self and a conferring of power on the other. For children who are avoided, power again remains with their peers. Only through subjugation of the unique self is there any chance of meeting the standards of behaviour and 'normality' necessary to establish friendships (Billington et al., 1998). For children with disabilities, they may remain 'the other' who is either expected to change and therefore conform or to remain separate from the type of friendships they may wish to have.

Children often rely on adults to assist in negotiating relationships with other children and particularly relationships with other adults. The need for adult physical or learning based assistance, compounds this reliance for children with disabilities (Shaw, 1998). The accompanying adult may negotiate children's relationships with others. Adults often act as gatekeepers in relation to the style, duration and frequency of peer interactions (Brown & Cohen, 1996; Pellegrini & Bjorklund, 1998). Consequently,

children may experience limited opportunities to negotiate and develop friendships in ways that are meaningful for them. Friendships may become the adult's perception of children's desires and needs (Baker & Donnelly, 2001; Skar & Tamm, 2001). Children may remain under the gaze of the adult world both within the classroom and the playground (James et al., 1998).

As children become older, a friend or a peer nominated by the school and the parent may provide aspects of school assistance required by children (Priestley, 1999). In either of these situations the 'helper' child may assume control in the relationship, placing a child with an impairment under the gaze of another when not under the gaze of an adult (Foucault, 1977).

Children's family, school and peer group contribute to children's perceptions of themselves. Each microsystem constructs a set of beliefs and values to which children respond (Bronfenbrenner & Morris, 1998). For example, predictable and nurturing family relationships become a basis for the understanding of the self as a loved and valued member of society. If the school environment is physically and socially accessible it reinforces acceptance of children's selves as having value within that context. Agency and respect from others, especially peers, contributes to a strong social identity (Bandura, 1986; Maslow, 1970). Certainly, positive constructs of one's cognitive, social and physical abilities, and ability to impact on the world would aid the expression of spirituality, and be reflective of its embodiment.

Agency and Disability

Society marginalises children with disabilities (Aptekar, 1986). These children are socially disempowered through being viewed as in need of additional care and

protection (Priestley, 1999). They are not generally perceived as resilient; nor are they perceived as agentic. Therefore, they must not only deal with the common adversities of life but also with society's perception of their lack of power and emotional fortitude, and the consequences of that perception. These perceptions curtail the freedom of children to express themselves and to experience risk (Bandura, 1986).

How then do they develop a sense of agency, in the broader or more specific sense? Society's understanding of marginalised children is often from external observation, thereby creating a reality of their lives shaped by others (Aptekar, 1986; Coles, 1989; Glauser, 1990). Adult responses to this perceived reality may validate initial misperceptions (Bandura, 1986). Societal norms that judge children as being different, in a negative sense, need to be altered. Children need to be understood and related to as unique persons with potential (Moustakas, 1959). If, as adults and professionals, we retain our openness to considering alternative views presented by children then we can develop an understanding of identity that encompasses their desires for agency.

Children need to experience a sense of agency in a way that is meaningful for them (Rogers, 1951). Children's understanding of their ability to be agentic depends on how capable they perceive themselves to be in relation to what they want to achieve (Bandura, 1986). If children believe in their agency then they will make choices that enrich their development, whether these are negotiating environments or tasks. Wider experience enables children to gain further knowledge of their capabilities and preferences, as well as the responses of the environment to their efforts. Children who perceive themselves as agentic are also more likely to persist with difficult activities and

will seek to overcome obstacles rather than be defeated by them. Agency, therefore, reflects a belief in the self.

Recent childhood studies of disability (e.g., Connors & Stalker, 2003; Shaw, 1998; Shevlin et al., 2002) give precedence to the voices of children. This research is challenging societal perceptions of children with disabilities, enabling children to express their knowing rather than responding to the imposition of adult-constructed knowledge. There is a growing body of research on children without disabilities who are also experiencing self agency issues, which resonate with other ways of being in the world. For example, street children (Felsman, 1989; Glauser, 1990) and children within cultural minorities (Coles, 1986, 1990) provide examples and phenomenological support for talking with and listening to children with disabilities, enabling children's identities to be heard and the complexity of identity formation to be explored. Positioned within this listening, we must not neglect the importance of the influence of children's selves upon their identities and the world in which they live (Bronfenbrenner & Morris, 1998; Prout, 2000).

Resilience and vulnerability. Children adapt to situations they perceive as stressful, and sometimes choose to place themselves in challenging positions (Garmezy, 1996; Weisz, 1990). Researchers have explored issues of resilience, vulnerability and risk, including those of disease/disorder (Grey, Lipman, Cameron & Thurber, 1997; Northam, 1997; Wilkinson, 1988), environmental factors (Bronfenbrenner & Morris, 1998; Coles, 1989) and coping patterns (Dugan & Coles, 1989; Seligman, 1995). Whatever the cause of adversity, in order for children to be resilient and to continue to take risks, they need to sustain their sense of agency. "The power of chronic and

cumulative adversities" (Garmezy, p. 11) places any child at risk of losing this sense of self. Garmezy viewed children's responses to stressors as denoting their resilience or vulnerability, with those children who demonstrated adaptive behaviours exhibiting resilience.

Resilience is linked with children's coping ability in both the external social world, and in their internal world where ethical and emotional conflicts are resolved. Coping strategies, belief systems, and the ability of children to regulate their behaviour to achieve positive outcomes impact on social skills (Bandura, 1986; Watson, Nixon, Wilson & Capage, 1999). However, these personal skills are necessary, independent of the social outcome. Researchers have shown coping skills to be independent of positive social conditions and intellectual abilities, indicating there are other factors to be considered (Coles, 1986, 1989; Haan, 1989). These skills may be experienced through children's sense of agency and their ability to utilise resources within the self.

Children may be vulnerable to the world in general or may experience vulnerability only in specific situations (Hunter, 2001; Seligman, 1995). Vulnerability speaks of challenges to the self in which children feel helpless and powerless (Haan, 1989). Recurrent social experiences that position children with disabilities as powerless, may construct an identity of helplessness. They may struggle with experiencing a sense of agency in their relations and may lose their sense of self within the expectations of others.

The affordances and resources at children's disposal, coupled with an impairment, create a knowledge base for interaction that is potentially different to that of children without disabilities. With this alterity of being comes a unique set of

experiences and skills, which contribute to children's sense of self and sense of agency within the world. Unique skills and resources influence the processes children undertake – the interactions they have with others and with the environment at large. The demands of children on their world through their understanding of the self and their sense of agency, as well as the demands placed upon them by others within their world also influence the quality of the processes children experience (Rogers, 1951). Here again we see the interrelatedness of each with the other (Merleau-Ponty, 1962, 1964) contributing to children's sense of resilience and vulnerability in their everyday lives.

One of the central concerns of this thesis is to explore how children are able to retain their resilience when confronted with 'chronic and cumulative adversities'. An ability to access spirituality may support resilience and thus sustain a sense of purpose (Coles, 1986, 1990). There may be an ability to sustain a sense of agency through knowing one has the inner resources to cope, and therefore to sustain the sense of self. Thus, even though there may be a paucity of external protective factors such as dependable and consistent care, societal acceptance, and perceived competency by others (Garmezy, 1996; Hunter, 2001), spirituality may enable children to sustain themselves in times of vulnerability.

The lived relation of children's experiences is the experience of the body placed between and within the world and the self (Merleau-Ponty, 1968). The self's knowing and the world's knowing constitute the inscription of meaning on the body through impairment and disability, how do these two intersect? How does spirituality as an embodied quality influence this relation? This thesis will explore these questions through the narratives of the research participants.

The Teller's Truths

The teller's truths were in the story too.

(Lee, 1999, p. 70)

Occupational therapists' personal beliefs about children with disabilities impact upon professional behaviour, consciously or unconsciously. We need to remain aware that we cannot completely divorce our professional self from our personal self in a therapeutic situation (Piper, 1999; Toller, 1999). If we consider children to be agents of their own lives, who have the inner resources to meet the challenges of their lives, then we will interact with them in a way that reflects this knowing. However, if we consider them to be always in need of our guidance, from the physical to the emotional aspects of their lives, then we will develop a relationship with them that positions them as relatively power-less and will only perceive them in that role. Children will find it extremely difficult to change our perceptions, supported as those perceptions are by societal values. We will also find it difficult not to impose significant constraints upon their identities through our expectations (Davies, 2000). We can choose to sustain the therapeutic relationship at the professional level proscribed by developmental theories and the medical model of disability, but we may never understand the cost to children's identities.

If, however, we choose to connect with children's experiences of themselves then we can approach the relationship with a greater openness of our own self to what may happen and what we will learn (Rogers, 1951, 1961). Here children are not simply 'disabled', but unique selves who can participate fully in the relationship if they choose, where choices become interactive rather than only from our directive. Children bring to

the therapeutic relationship knowledge of their identities, difficulties and pleasures, and their desires for what is important to face, to leave, and to consider.

The positivist model of science, and consequently of therapy, is slowly changing but it still carries a mantle of knowledge that discounts the inner knowing of children's selves. This thesis takes the view that we cannot separate science from philosophy because the experience and understanding of science are viewed through the self (Helminiak, 1996; Merleau-Ponty, 1962). Thus science is not the objective device we might wish it to be. To understand the world more clearly we need to move beyond the perceived rationalism of science, or risk removing ourselves from understanding the multidimensional ways of being inherent in the world of children (Merleau-Ponty, 1964). Children's identities would then remain concealed from our knowing by the veil of our expectations.

As the storyteller in this thesis, the narrative I presented in Chapter 1 of two children with whom I have worked encapsulates for me many of the experiences I have had in my professional role. The narrative summarises meeting and spending time with children who teach me about other ways of being, whose lives are so different from my own. Children who do whatever it takes to make themselves heard and to live the lives they wish to live. They teach me about respect, joy, caring and grief. They smile when I arrive, hug me, laugh, joke and love to learn. They hit, bite, disagree and resist me. They are 'too quiet' and 'too good'. They are sad, angry, fearful and withdrawn. They challenge my professional and personal thoughts of who they are and what they need from me. I have known many children, from those who were dying to those who couldn't coordinate well enough to play handball at recess. My truths come from my

work and from my personal life; each has facilitated the other over the years. As I have grown so has my desire to know how to help children on a level far deeper than that of providing them with an adapted pencil. I know that the warmth and trust a child and I share is a gift we give each other. Our brief connection is very real and very powerful, enabling both of us to learn a little more about the world we live in and to discover a little more about ourselves.

Like my contemporary colleagues, traditional developmental theories and the medical model of disability shaped my professional views of children and impairment. The professional world in which I practiced supported these views. But my experiences with children would not let me ignore their needs, needs that I had to respect and address if I was to help them in a way that was meaningful and enabling for them. That adapted pencil was literally going to get thrown out of the window if I didn't listen to the way in which a child was trying to tell me how it would separate him or her from belonging in the classroom, if the message that pencil was carrying was how he or she had failed yet again. I needed to accept children's visions of and for themselves, to learn to work with their knowing of themselves, not against it.

As a relatively new approach to occupational therapy thinking, occupational science draws together interdisciplinary perspectives to better understand the meaning of people's lives (Zemke & Clark, 1996). To develop the knowledge that generates practice, it is necessary to draw on diverse fields of thought about the contexts of the lives of children with disabilities and how these are interwoven with the negotiation of identity. If that knowledge is available to us, or needs to be developed, then it is our professional responsibility to engage in discourse and research to provide more

meaningful interactions and collaborative partnerships with children within their worlds. Stepping outside the boundaries of traditional viewpoints of children with disabilities can only enrich our understanding of their needs and desires for themselves, this in turn enriching our relationships with them and the services we seek to provide for them.

A spectrum of perspectives can be explored through phenomenology, improving our experience and understanding of the lived experience of disability and identity (Merleau-Ponty, 1962). In our practice, we need to extend this understanding to children, to understand their past, presents and futures, their beliefs and values, and their desires in social relations. Although this may make our experience initially more confusing as it broadens our view, it also has the ability to enrich it in ways we had not considered. The experience will be richer and broader for each child, and understandings may be shared by a child and the listener. There is not a single truth, and we should acknowledge that children's truths of the world are as valid as those of adults, facilitating our comprehension and compassion for children's ways of being in the world.

Any therapeutic relationship with a child is significant and one that can hold much power; power for the child to find purpose, courage and joy, thereby positively influencing his or her motivation and willingness. Through our faith in children we enable them to take risks, to want more in their lives and from themselves. In our ability to connect with them we enrich their ability to connect with others. Through our belief that engaging in meaningful activity will help them to build a bridge to themselves and to others, we help them to find the power to do so within themselves.

This thesis explores the contribution of spirituality to children's identities and occupational engagement. Occupational therapy has been focused on 'doing', utilising techniques to facilitate functional skill development. However, children's engagement with the world encompasses more than the ability to 'do'. Jacob's motivation to 'do' so much with limited physical skills (see Chapter 1, opening narrative) calls us to question our focus on skills. His being in the world urges us to consider the importance of identity formation, and the contribution of agency to children's experiences of resilience. How we can facilitate children's resilience, especially within experiences of vulnerability, challenges us to consider the role of spirituality.

Children who are able to access their spirituality may experience greater resilience in their lives than children who cannot. Through being able to connect with and utilise their spiritual qualities for their own purpose, these children may be more likely to take risks knowing they can cope, and more likely to be fully engaged in life and to want to be so. The children we see are often not listened to and are expected to be passive. Our current engagement with them does not consciously engage or nurture their spirituality. We need to listen rather than taking a directorial role with them. We need to let them lead, to show us how they find meaning and to embed that meaning in their interactions with us.

Chapter 3: The Embodiment of Spirituality

When through the water's thickness I see the tiling at the bottom of a pool, I do not see it *despite* the water and the reflections there; I see it through them and because of them. If there were no distortions, no ripples of sunlight, if it were without this flesh that I saw the geometry of the tiles, then I would cease to see it *as it is and where it is* . . .

(Merleau-Ponty, 1968, p.182)

Theoretical understandings of spirituality shape occupational therapy's professional gaze and how we reflect upon them within our relations with children. The expressions of lived experience are the sunlight and distortions that enable us to see the spiritual dimension within ourselves and our relation with others. How we gaze upon the embodiment of spirituality will mark how we perceive its lived expression, and how spirituality (the tiles) is reflected through a child (the water) to our eyes.

Ideas about children's spirituality are known largely through the writings of religious and moral thinkers that place children's understandings and expressions within developmental models. From those who have listened to children, other understandings of children have arisen. Some of the most important of these ideas will be outlined below. Exploration of spiritual qualities may enable children's experiences and voices to become a source of knowledge that in turn influences the frameworks of professional practice.

The concept of spirituality will be clarified by identifying the nature of spiritual qualities. Within the understandings of qualities such as belonging, hope and trust, there lies a commonality of meanings and expressions. Although the expression of spirituality is bound by culture, meanings transcend religious and cultural boundaries, and the expressions are at once common and unique to each person. The lived expression of spiritual qualities is embedded in the daily rituals, rhythms and challenges of life for

children, as it is for adults. How we reflect upon and thus understand these expressions contributes to our knowing of children's spirituality.

The Shaping of Thought

Occupation brings meaning to life.

(Canadian Association of Occupational Therapists, 1997, p. 36)

Meaning also brings life to occupation. Occupational therapy's focus on meaning through engagement opens a door to a more detailed consideration of spirituality. Purpose embodied through meaning gives each of us the motivation to keep trying, to endure life's difficulties, to feel that we are making a difference to ourselves and others (Carpenito, 1995), to engage with the relations and occupations of our lives. Through this purposeful journey, life's meaning becomes more evident and supports our development.

Although there are occupational therapy models that incorporate the importance of values and beliefs (e.g., Kielhofner, 1995), two occupational therapy models explicitly discuss the 'place' of spirituality in people's lives and within occupational therapy practice. The Canadian Model of Occupational Performance (CMOP) (Canadian Association of Occupational Therapists, 1997) and the Occupational Performance Model (Australia) (OPM (Aust.)) (Chapparo & Ranka, 1996) present the influence of spirituality in differing ways, but both clearly discuss its importance within the experiences of those with whom we interact.

The CMOP (Canadian Association of Occupational Therapists, 1997) conceptualises spirituality as the core of a human being. This core represents the 'essence' of being human and is the primary force within the three aspects of person-environment-occupation. That is, spirituality is within the person, is influenced by the

environment and gives meaning to a person's being in the world. Spirituality is inherent in the occupational performance process through respect for a client's values, beliefs and preferences, choosing meaningful occupations in partnership with a client, and enabling a client's self-determination.

Through the CMOP (Canadian Association of Occupational Therapists, 1997), spirituality is at once the core (of the person) and the thread (linking the three concepts together) evoking a relational quality of connection with the self and the world. In the words of Victor Frankl (1997), "By being centered around the existential, personal, spiritual core, being human is not only individualized but also integrated." (p.34). This individualised and integrated humanness interacts with the world, with the spiritual core being the "essential ground" (p. 34) on which the self stands. For Frankl the integration of mind-body-spirit is essential to humanness, but he considered the spiritual centre to be "encompassed by the peripheral somatic and psychic layers." (p. 35). Thus spirituality is embodied through being.

Within the OPM (Aust.) (Chapparo & Ranka, 1996), mind, body and spirit are core elements, which are interrelated, with spirituality "within all aspects of occupational existence and expressed in all constructs of the model" (p.12). Spirit is the 'being' dimension of occupational performance and is "defined loosely as that aspect of humans which *seeks* a sense of *harmony* within self and between self, nature, others and in some cases an ultimate other; *seeks* an *existing mystery* to life; *inner conviction*; *hope* and *meaning*" (p. 13). Ways of being are presented within the concepts of 'felt space' and 'felt time'. These concepts resonate with the existential themes of 'lived space' and 'lived time' (van Manen, 1990), which express spiritual connections through their basis

of meaning for the individual. The model presents some connection between spirit and the lived experience of spirituality through its discussion of hope, meaning and interconnectedness, and through *loss* of spirit – “loss of hope, loss of resolve, loss of ‘connectedness’, loss of purpose” (p. 14).

The OPM’s (Aust.) (Chapparo & Ranka, 1996) focus on the spiritual qualities of hope, purpose (meaning), faith and courage (resolve) and belonging (connection) provides a restricted understanding of the depth and breadth of the significance of spiritual qualities in a client’s life. There are other equally important qualities, including trust, joy and compassion. How we translate the ‘core element’ of spirit into daily practice is thus also restricted. Phenomenology provides a way of understanding the lived experience in further depth and thus with a fuller understanding of the interrelatedness of mind-body-spirit (being) with the world. For example, as we explore children’s intentionality, it leads us to consider how agency expressed through action and choice gives rise to the enactment of purpose.

The CMOP (Canadian Association of Occupational Therapists, 1997) and OPM (Aust.) (Chapparo & Ranka, 1996) do not fully enable us to understand the significance of spirituality within the lives of children because they have not been sufficiently definitive about spirituality, its qualities and embodiment. Phenomenology provides a key to understanding how the thread of spirituality is acted out in the context of children’s lives and relationships. The interrelatedness of the self and the world is central to phenomenological philosophy (Merleau-Ponty, 1962). Thus the thread of spirituality weaves its way between the spirit and the world known to the self,

manifested through children's choices, hopes, decisions and engagement in all areas of their lives.

Each child experiences the world in a unique way, which incorporates the social and cultural foundations of the self. Children's worldviews therefore, come from being in the world and the world being in them; thus intentionality and therefore identity shapes and is shaped by the world. One of the challenges for our profession is to understand the effect of practice on shaping the child's self as an intentional being, foregrounding the relationship rather than the child as an object of intervention.

A phenomenology of spirituality offers a more detailed insight into the embodied nature of spirituality in the everyday lives of children. We are assisted in understanding the everyday lived experience for children and the process whereby they articulate their sense of self in an often unreceptive world. If phenomenology is a lived relation to the world through a creation of meaning, then it relates to children's ways of being in and understanding the world, and how they view their world (Merleau-Ponty, 1962, 1964). The body is the intermediary between the self and the world; just as the self (including the expression of the body) is the intermediary between the spirit and the world. The intertwining of spirituality, self and world brings consciousness and intentionality as an expression of purpose to the self.

The concept of spirituality is often perceived to be abstract, but it can become more 'concrete' through awareness of its lived expression. We can integrate our awareness of spirituality via an openness towards children's being. We need to acknowledge and respect children by bringing receptiveness to our mode of inquiry in our practice. Constructive discourses within the profession speak of a changing of

perception, leading to the development of theoretical models that embrace the significance of spirituality. However, occupational therapy models under-theorise the self within occupation. Phenomenology offers a way of extending our thinking about the nature of selfhood for children via intentionality.

Intentionality brings to awareness the ways of knowing the self in relation to the world (Merleau-Ponty, 1962). Children's intentionality seems to presuppose engagement. Non-engagement keeps the world at a distance, but implies that consciousness is still directed towards the world. Jacob and Ben (see Chapter 1, opening narrative) chose to engage/not engage, which implies intention, and is therefore a lived relation to the world. Thus the intentionality of engagement and non-engagement forms the basis of their knowledge of the world, and the worlds of other children. For all children there is a knowing of themselves and the world outside of their experiencing and knowing of the medical and social constructions of disability. Here the self is engaged with the world beyond the bounds of being identified by knowledge outside of the self (Merleau-Ponty). Spirituality assists children to understand their ways of being, with spirituality expressing itself through lived experience.

Developmental understandings. The most extensive work carried out to date in relation to children and spirituality has been from the focus of Christian faith development (Fortosis, 1992; Fowler, 1974; Helminiak, 1996). This research and theory defines the Western, adult view of children's understanding and expression. Religious understandings of children foreground the development of cognitive abilities as a prerequisite to the 'correct' understanding of religious concepts.

The presentation of Christian spiritual development places children at the embryonic stage of spiritual knowing (Fortosis, 1992; Fowler, 1974; Helminiak, 1996). Spiritual understanding is seen as something that can only be developed with time. Within these theories, children cannot be viewed as complex spiritual beings. Rather, their challenge is to interpret their spiritual knowing through the adult lens of religious faith. As with cognitive and moral child development theories, these theories of religious faith are temporally sequential, placing the development of adult understanding at the pinnacle of the religious power structure.

Social constructs, and consequent internalisations of morality and its (judgemental) companions of fear and anxiety by Piaget (1932), Vygotsky (1978), Kohlberg (1964) and Erikson (1963) position children as unknowing of themselves. Such positioning of children precludes those who do not master adult values of intellectual development from being considered as having emotional knowing, particularly in terms of understanding and relating to themselves and others. For example, according to Piaget's (1955) theory, affect and intelligence are intricately interrelated. However, it could be argued that the cognitive intelligence Piaget highlights is distinct from the intelligence of the heart and spirit needed to respond affectively. The alternative proposal considers that children have an ethical understanding based upon their spirituality, and they experiment with how their ethical views can be expressed and find congruency within societal morality (Coles, 1986, 1990).

Theorists have assumed children must achieve a certain level of cognitive maturity before adults accept that children have knowledge of themselves and their spirituality. Often this level of acceptance is based on children's verbal responses and

ability to explain abstract thought. The ability to value children's spiritual knowing is constrained within the arbitrary boundaries of psychological and sociological developmental research that seeks to measure and objectify a highly subjective area of experience.

Spirituality is often a concept that exceeds capture as 'fixed' knowledge. The individual meaning of spirituality within everyday experiences enables understandings of its embodiment. Children's use of language, embedded with personal meaning, is an example of the expression of spirituality, but one that needs to be considered within the context of the speaker. Language, whether written or spoken, can only attempt to convey the full meaning of feeling or understanding but can never precisely emulate it (Ricoeur, 1992; Riessman, 2002). There is a need to understand the hidden elements of the speaker's words (Hillman, 1989). Within the interaction of children and adults, understandings of meaning within language may differ significantly (Coles, 1990; Hart, 2003; Nesbitt, 2000). However, the expression of spirituality occurs not only through language but also through all aspects of the self's participation in being in the world (Zukav, 1989). Thus, spirituality is also reflected in children's relationships, play and learning.

The extensive work of Kubler-Ross and her colleagues (1969, 1975, 1981) was instrumental in challenging Western society's beliefs regarding the understanding of children. Her work presented the ability of children to express their philosophical understanding and spiritual connections in the midst of deep suffering through the use of "nonverbal symbolic language" (Kubler-Ross, 1981, p. 19) such as drawing, painting and play with representational objects. Her work opens up a space for adults to

remember the language of childhood that can enable greater knowing, respect and engagement with children. The onus is on the adult to know the language of 'the other', even as children try to express themselves as well as they can within their own 'language' (Ryan & Stower, 1998). Children experience spiritual distress when they are not supported to express their understandings and/or their expression is not accepted by others (Carpenito, 1995; Ryan & Stower).

The Practice of Spirit

Spirituality is *the practice of spirit*-the conscious, goal-directed activity which brings spirit and soul into being.

(Kovel, 1991, p. 198)

Coles (1986, 1990) spent many years interviewing children about their views of life and themselves. These children lived in segregated societies, rich and poor neighbourhoods, rural and urban landscapes, in war and peace times. The dialogues documented in *The Spiritual Life of Children* (Coles, 1990) demonstrate the influence of their cultural and religious backgrounds. Common spiritual underpinnings weave their way through each child's story. Children from diverse religious backgrounds spoke of the central importance of connection with family, community and caring for others. Children living in segregated societies as well as those who were part of societies whose religious beliefs could not be separated from their connection with nature, expressed their views of love and compassion for others and the world. The importance of a relationship with a divinity (or divinities) is evident in their religious understandings, as is the impact this relationship has upon their actions. Central themes included God's (or another divinity's) role in their life and what the children needed to do in order to live in harmony with the divinity's teachings.

These children questioned the meaning of life and significant life experiences, and connected their personal philosophies with their everyday lives. All of the children pondered, discussed and wrestled with theological issues, blending these into discussions of what they were meant to become when they grew up, the way the world was and the way they wished it could be. Their philosophies wove their way into conversations about their relationships with their families, peers and communities, the disagreements, aspirations and challenges to their sense of self-knowing. The questioning and discussions of these children reflect understandings positioned outside of the traditional medical and social constructions of childhood. These understandings challenge the positioning of children's knowledge as lesser than adult knowledge and highlight that children need to be listened to by the adults they encounter (Merleau-Ponty, 1964).

For those children who had not been part of a religious upbringing, the same need for purpose, ethical congruence and connection with others and the world was also evident. Although the expression of these themes was outside religious boundaries they were still centrally important to the lives of these children. These children also considered the apparent divorce of religious beliefs from lived beliefs within the practices of their societies. They preferred to live out their spiritual understandings in ways that were authentic for them, for example, through caring for their family and establishing ethical relationships with peers.

The work of Coles (1990) with children from different cultural and religious backgrounds compliments the work of Robinson (1977) and Hart (2003). Respondents in these works identified a sense of purpose, connection (to others, a divinity and nature)

and faith that was part of their inner knowing in the days of childhood. That spiritual knowing is not tied to religious education, cognitive or emotional development is inherent within these narratives of childhood (Farmer, 1992; Ryan & Stower, 1998). The children interviewed by Coles were able to articulate their understanding of spirituality within the very personal perspectives of religious and cultural beliefs. Ultimately, children's expressions of spirituality were as varied as their lives.

Spiritual qualities. Everyday negotiations with family, friends, teachers, peers and neighbours evoke the embodiment of spiritual qualities. Children draw upon spiritual qualities to meet the challenges in their life as well as to offer love and friendship to others. Current understandings of the embodiment of spirituality for children do not encompass an understanding of the contribution of spirituality to the construction of identity, agency and resilience for children with disabilities. Broadening and deepening occupational therapy understandings will help us to recognise and build upon spiritual qualities with children like Jacob, and enable us to assist children like Ben to use their spiritual qualities to engage with the world (see Chapter 1, opening narrative).

Spiritual qualities are enacted within the lived relations that shape identity. These qualities are both 'inner' and 'outer', developed and performed through engagement in everyday relationships. They are not separate from children's immediate worlds. Rather, through the self, they are intimately entwined with others and the lived experience of being in the world. Most readings on spiritual qualities are presented in relation to adult experiences. However, I have chosen to relate the following discussion to children's

expression, to develop a greater understanding of the embodiment of children's spirituality.

What spiritual qualities underlie the expression of the self? I searched across diverse treatises and traditions, for example, Christian (Tillich, 1952), Judaic (Fasching, 1992), Hindu (Mascaro, trans. 1962), Muslim (Ali, trans. 2000), Buddhist (Dalai Lama, 1996), Taoist (Tzu, 1963), Native American (Gold, 1994), and classical (Wittgenstein, 1968) and contemporary philosophical texts (Moore, 1992). In my search, I uncovered common ground within which I identified spiritual qualities. These qualities are considered to be inherent and inter-related in all human beings.

The interweaving of spiritual qualities within lived expression speaks of a relational experience of spirituality with the world, an experience that is fluid in its expressions and responses. Thus spiritual qualities affect identity, and consequently the contexts of family, school, community and society (Zukav, 1989). In the following discussion spiritual qualities are presented in italics. The references supporting the definitions of the spiritual qualities represent a distillation of those writers who most clearly defined the meaning of each quality and its embodiment.

Children need to experience a sense of *belonging* through connection with others, to develop the self on a foundation of emotional security (Bollnow, 1989a). The need for belonging is experienced through children's needs for safety and trust in those around them (Maslow, 1999). A foundation of emotional security can help children to remain resilient in times of distress, loss and betrayal, where they experience a loss of trust in the world.

Spiritual well-being depends on children's connecting with others, nature and perhaps a divinity. Through their connection with others children are able to give and receive that which they need to sustain them. This support may be spiritual, emotional or physical. Connection with others enables the development of a sense of community, even among people of different beliefs, through love and compassion. A connection with nature can nurture the spirit when connections with others are fragile or the world seems too demanding (Moore, 1996). If there is a belief in the existence of, and connection with a divinity, then this connection can provide support through faith in the ultimate benevolence of that divinity in times of crisis and trauma (Dalai Lama, 1997; Hardy, 1979; Whelan, 1994).

Love in the spiritual sense is unconditional, a giving to another without expectations of return (Vardey, 1995). Felt for the self and others, it encompasses belonging, joy, trust, compassion and faith. In religious faiths it is often expressed in relation to a divinity towards an individual. Love for another sustained even in times of loss or abandonment is love on a spiritual level (Weil, 1952). At an individual and collective level, children's connection to others through love and trust (Borysenko, 1990) creates relationships that respect and nurture all involved. These relationships provide an important source of resilience in times of vulnerability.

Grace is an extension of love (Borysenko, 1990). Children offer grace to others and others to them through acts of love (Vardey, 1995). Grace may be experienced through kindness, unexpected support, or the easing of a difficult experience. In religious faiths it has been expressed as a divinity's presence in children's lives (Finch, 1999; Pieper, 1963; Weil, 1952) and is experienced through the support and care of this

relationship (Borysenko; Finch). Grace is seeing the beauty in life (Borysenko; Friesen, 2000) and seeing life as a gift (Finch; Pieper; Weil). Grace enables a viewing of life from a perspective of clarity, reaffirming faith and hope in the journey (Friesen).

Consciousness is the self's awareness of the spirit, and awareness of the spirit in others (Dalai Lama, 1996; Helminiak, 1996). Identity is not simply a 'reaction' to internal and external emotional forces or circumstances (Freud, 1984), but a response to a deeper understanding of the needs and expressions of the self (Zukav, 1989). Consciousness gives rise to spiritual agency through the response to the self and to others. Consciousness towards others may evoke compassion and love, and create a sense of belonging.

Compassion towards the self and others enables children to forgive expressions that harm them, whether it is forgiving themselves or forgiving others (Borysenko, 1990; Dalai Lama & Cutler, 1998; Goleman, 1997). Children's understanding and acceptance of others whose realities and needs are different from their own is promoted through compassion (Connors, Toscova & Tonigan, 1999; Dalai Lama & Cutler). Consciousness is a recognition of the self's capacity for fear, doubt, jealousy, or anger. Learning how to forgive the self assists children to extend compassion and forgiveness to others (Dalai Lama, 1996).

Ethics based on compassion considers the needs of each person and the consequences of his or her actions on others (Dalai Lama, 1997). Therefore, ethics based on the obligations of each child towards others, respecting the other without forgetting the needs of the self, builds an inclusive sense of justice. Relationships built on compassion and concern for others and for the self (Zukav, 1989), provide a balance

within which each child can be heard and seen as a unique human being who has much in common with others (Dalai Lama & Cutler, 1998). When children understand relationships, based on love, it brings forth justice (Finch, 1999).

Purpose encompasses intention and is embodied through meaning, experienced in everyday acts. Children may find purpose in connection with others, desires for the self or the desire to give to others. In a larger context it is experienced as the meaning of life's journey (Hillman, 1989). Meaning enriches life's experiences, enabling each child to find purpose in being, whether this entails joys or trials, or simply daily routine (Finch, 1999; Myss, 1996). Finding meaning in daily life also strengthens children's resilience within the experience of suffering (Miller & Thoresen, 1999; Yahne & Miller, 1999). Purpose enables children to transform suffering into meaning, becoming the embodiment of faith and an ongoing source of strength (Dalai Lama & Cutler, 1998; Frankl, 1959; Mackey, 1983; Vardey, 1995; Weil, 1952). Kubler-Ross' (1969, 1975, 1981) work with children who were dying brought into sharp relief their ability to find purpose in suffering and to be able to die in a state of serenity.

Hope is a belief in life, trusting that life has purpose and therefore meaning (Friesen, 2000; Vardey, 1995). Children experiencing hopelessness see a lack of life and joy facing them, which creates a vulnerability of self. When children find meaning it can create hope, a realisation that each ending or loss is also a beginning, renewing a sense of purpose in life. Hope is expressed through action, "the will to live, to survive, recover, or to learn" (Yahne & Miller, 1999, p. 220). Hope supports resilience in adversity and sustains a belief in the self and the world.

Faith and courage are interwoven with hope. *Faith* can be defined as having a belief in, or *trust* in, the presence and assistance of a divinity (McGrath, 1999; Yandell, 1999) or more broadly as the capacity for children to trust in themselves or another (Connors et al., 1999; Dalai Lama, 1996; Friesen, 2000). Hope and faith are entwined with empowerment. They enable children to believe in their power to achieve, to trust that they have the resources to cope and to grow (Yahne & Miller, 1999). Trust and faith are intertwined, giving a "deep confidence in life" (Moore, 2002, p.46). *Courage* draws together trust and hope enabling the will of the self to be expressed even in times of fear and doubt. Courage is known as the "self-affirmation of one's being" (Tillich, 1952, p.3).

From compassion and courage springs *wisdom*. Wisdom is a depth of understanding of oneself and others woven with compassion. Through wisdom, children can engage their spirituality to see the truth in the self and others, and wisdom is partnered with children's ability to view the broader purpose in life's journey (Hillman, 1989).

The qualities of awe, wonder, and joy reflect a suspension of self and an immersion of the spirit in experience, creating a profound sense of connection and awareness in which the self is silenced (Pieper, 1963). *Awe* and *wonder* are dimensions of seeing, knowing, touching and being touched by the world. They are enfolded with and expressed through joy (Cobb, 1977). In these 'existential moments' (Moustakas, 1973) there is an "opening of a dimension that can never again be closed" (Merleau-Ponty, 1968, p. 151). A *transcendence* of self occurs that causes a stillness within the

self as it opens to the world (Fullagar, 1998). Transcendence is an experience of transformation through which the self develops in relation with the world.

Joy speaks of transcendence, where the self becomes 'more than and at one with' the spirit and world (Ackerman, 1999; Weil, 1952). The joy of humour and playfulness creates an engagement with the world based on an openness of spirit. Children's ability to learn and their desire to develop the self may be grounded in a joy of living supported by a feeling of security, or sense of meaning in the world (Maslow, 1999). Joy, love, trust and hope (Bollnow, 1989a) are essential to children's well being and development of identity. They nurture children's belonging through connection with others and give them a sense of purpose in life.

Creativity encompasses and draws into being many other spiritual qualities, including purpose, joy and belonging (to the self and the world). Children give this gift to themselves and others (Vardey, 1995). Like joy, creativity speaks of a suspension and immersion, where the spirit is freed and shines through the self, be it through art, music, dance, imagining the world in a different way (Moore, 1992), or living in one's own way (Moustakas, 1967). Creativity embraces "adaptability, flexibility, ingeniousness and resourcefulness" (Sheldrake, 1989, p.317).

Creativity and joy are often experienced in flow (Csikszentmihalyi, 1990) and reflect the embracing of life by the spirit (Borysenko, 1990). When children experience life as a gift, with grace, it fosters engagement in activities that support the growth of the self, whether these activities are easy or difficult, provide immediate growth or are part of longer term growth. Children may then grow in complexity through this choice of engagement, finding further richness by developing their potential in all areas of life

(Csikszentmihalyi, 1993). Csikszentmihalyi (1993) equated this with Maslow's (1970) self-actualisation theory where a child is being all he or she wishes to be at any moment in his or her life. This experience relates closely with joy where, as Weil (1952, p. 73) states, "Joy is the overflowing consciousness of reality". The embodiment of the spiritual qualities of love, joy and belonging assist in building resilience and self-esteem while alleviating the impact of emotions such as despair, anger and hopelessness (Friesen, 2000; Hunter, 2001).

Flow is most evident in children when they are at play, where the self is absorbed in the activity and forgotten (Csikszentmihalyi, 1975). Play can be a vehicle for expression and connection to the spirit and to the world, providing a space to consider and reframe the world. Play used by children for this purpose has been documented by developmental theorists, psychologists and psychiatrists (Axline, 1964; Montessori, 1966; Moustakas, 1959; Winnicott, 1964). Moustakas acknowledged the necessity of play without rules for expression of the spirit outside of the confines of society, to sustain the spirit. Campbell (1959) termed the ability to play as a "nobility" of the spirit (p. 27) where the spirit is free to transcend the reality of the world.

For all children there are also daily experiences that have personal meaning, that satisfy the spirit's yearning for expression and connection. Hallmarks of these experiences may include feelings of agency, grace and extending the self, feelings that embrace the power of the spirit. The practice of spirit within daily life encompasses an engagement of the self with others and the world (Moore, 1996).

Agency is the expression of the spirit through positive choices, which meet children's needs for growth, while remaining conscious of the needs of others. The self-

esteem that arises from agency helps children to believe in the goodness and uniqueness of the spirit (Finch, 1999; Gold, 1994; Weil, 1952). Agency is also linked with self-esteem, as the self becomes a greater expression of the spirit and not what others wish the self to be; the self expresses and lives the spirit's purpose (Zukav, 1989).

Empowerment comes from enacting the spirit, rather than from another person (Borysenko, 1990; Zukav), becoming an expression of the spirit through the self (Moore, 1992).

Reflective Practice

Consideration of spirituality is essential in assisting the client to engage or reengage in occupation.

(Egan & DeLaat, 1997, p.116)

The question of how spirituality is 'considered' forms part of the discussions on spirituality in therapeutic practice taking place within occupational therapy literature. The profession is actively engaged in understanding and meeting with the spirituality of those who come within its care, highlighting the importance of spirituality in theoretical frameworks and practice (Kang, 2003; McColl, 2000; Rose, 1999; Unruh, 2002). Within these discourses, personal understandings of spirituality are apparent in the worldviews presented, through its perceived nature and expression in life (do Rozario, 1997; Howard & Howard, 1997; McColl, 2003). The lived experience of spirituality for adults has been of strong interest. Experiences have been explored within the therapeutic relationship and within the rhythms, challenges and relationships of adults' daily lives (e.g., Egan & DeLaat, 1994, 1997; Frank et al., 1997; Kirsch, 1996; Spencer, Davidson & White, 1997; Van Amburg, 1997; Wilding, 2002; Yerxa, 1998). However, the voices of children with disabilities are absent.

In response to the need for practitioners to gain a greater understanding of how spirituality impacts upon the lives of adults with disabilities or those experiencing illness, do Rozario (1997) and McColl et al. (2000) chose a similar path of investigation through qualitative research, but different paths of interpretation. do Rozario approached her research from a transpersonal phenomenological perspective. She focused on how adults embodied spiritual resources to facilitate a "sense of wellness throughout their suffering and coping" (p.431) and the ways in which meaning was created in the lived experience of their impairment or illness. McColl et al.'s research investigated spirituality in the lives of adults with an acquired impairment, identifying the factors that created change and gave meaning to their experiences within a relational framework. This research offered a taxonomy of spirituality and impairment that could be considered within the therapeutic relationship. Where the paths of these two researchers diverge is within the discussion of what spirituality is for their participants. do Rozario chose an encompassing but very personal view for each person. McColl et al. chose a more prescriptive view where each person's story was defined within more general psychological and religious terms.

The research presented by these two occupational therapists highlights the richness of each participant's story and the influence of each person's spirituality in his or her search for understanding of that story. The embodiment of spiritual qualities can have a significant impact on an adult's life. This has been highlighted in case studies in the occupational therapy literature (Clark, 1993; Peloquin, 1995), returning practitioners to the lived experience for people who have an impairment or experience trauma. The spiritual threads of belonging, purpose and sustaining a sense of self bind each

discourse, as does the implicit nature of spirituality in everyday occupation. The meaningfulness of everyday occupation interests all occupational therapists regardless of their worldviews on spirituality (Urbanowski, 2003).

The recent work of Simo-Algado and Burgman (2005) has begun the exploration of spirituality within the resilience and emotional recovery of children who have survived traumatic life experiences. The spiritual strength of children experiencing adversity is evident within Simo-Algado's work with refugee children in Kosovo, as is their desire to express, make sense of, and integrate their experiences. His presentations of the Kosovo children's narratives reflects the work of Coles (1990), highlighting the spiritual awareness and strength of children, and their desire to make meaning of their lives.

For children, being in the world may require great courage, a repeated delving into the spirit to meet the challenges of expression and growth. Our role is to assist children in this process, to respect their process and the 'lived space' and 'lived time' of that process. We know children from the habits of our (theoretical) perceptions (Merleau-Ponty, 1962), and hopefully also from the conscious, reflective acknowledgement of our own beliefs. Only children know their own being, perceived through their lived experience (Merleau-Ponty, 1964; Rogers, 1951).

Qualities of reflective practice are entering the therapeutic relationship with children, considering children within the context of their lives and assisting them to find purpose and joy. Within the therapeutic relationship, it is important that purpose is interwoven with hope through engagement in occupation. This practice respects the needs and desires of the children and the personal meanings of their daily lives.

Reflective and respectful practice enables the expression of children's spirituality within the formation of their identities in the world, through actions and relations with others and the self. Discourses on the art of practice are now influencing models of practice (Higgs & Titchen, 2001; Schon, 1987). The art of practice embraces reflection and wisdom, foregrounding the meanings of lives through narrative (Mattingly, 1998). When practice is 'considered' from the perspective of spirituality we have a limited knowledge of children and how we may enfold spirituality within the art of practice.

Seeking to understand how children with disabilities use spiritual qualities in their everyday lives leads to further questions. How do children with disabilities experience a sense of purpose within their worlds of home, school and community? How do they determine and express choice within the rhythm of their lives? How do they sustain and develop their sense of self within the relations of their lives? How are these questions intertwined with spiritual qualities?

I have privileged particular philosophical and theological writings in defining my understandings of spiritual qualities and their expression in the lived experience of children. The literature review has foregrounded these understandings. Although the research topic reflects my framework, my aim through the use of phenomenological enquiry was to open the space within which children with disabilities could express the meanings of spirituality within their lives.

As Frank (2000) stated, we each have a standpoint and it is this that must be reflected upon and made explicit, as I have tried to do in my writings. Ultimately, the thesis remains my interpretation of the children's narratives through the gaze of

spirituality constructed from the embodiment of spiritual qualities. In the following chapters I have focused the interpretation and discussion of the children's narratives around the spiritual qualities presented in this chapter.

The privilege of my position as an adult/researcher/therapist has shaped my understandings and approaches to both the research question(s) and the children. Thus, the importance of creating a shared space of understanding and reflection was of utmost importance if my position was not to subjugate theirs. I hope I achieved this, at least in part, though I acknowledge I could never do this in full. To think so would be to deny the lived relations of children and adults within our society, relations to which both the children and I are exposed and acculturated.

Chapter 4: Listening to Children's Voices

Listening to the voices and views of children themselves is one of the most neglected aspects of child development research.

(Greig & Taylor, 1999, p.81)

Within occupational therapy research children with disabilities are largely positioned as objects of interest (Graue & Walsh, 1998). The evaluation of assessments and functional outcome measures of intervention treat children as unknown, ignoring their active participation in life contexts. There has been a burgeoning interest in the narratives of adults with disabilities positioned within qualitative research paradigms (Mattingly, 1998; Mattingly & Garro, 2000) and of parents of children with disabilities (Case-Smith, 2004; Cronin, 2004; Larson, 2004; Segal, Mandich, Polatajko & Cook, 2002), but research that privileges the voices of children is rare.

As noted in Chapter 1, my objective was to listen more closely to the voices of children with disabilities. This focus created an imperative that I talk with them, rather than with their parents, therapists or teachers, to better understand their way of being. I approached them with a particular focus on their way of utilising spiritual qualities in their everyday lives. To elicit their voices I chose to situate my research methodology within hermeneutic phenomenology (van Manen, 1990). This approach would enable me to explore their lived experience through "the attentive practice of thoughtfulness" (van Manen, p.12) foregrounding their meanings and perceptions of themselves and their worlds, through engagement with and reflection on those meanings and perceptions.

The method was based on narrative conversation (Ricoeur, 1992; Riessman, 2002) incorporating play, art and photography, one that allowed the children to shape

their interests and become active participants in the research (Davis, 1998). By combining phenomenological and narrative approaches, I was able to explore the research topic in ways that sought to creatively meet the needs of the participants.

Due to the exploratory nature of the research, hermeneutic phenomenology enabled a circular process of enquiry to the research question. Eliciting children's thoughts and feelings on varied aspects of their lives drew together "possible experiences" (van Manen, 1990, p. 41) in turn enabling "possible interpretation[s]" (p. 41) of their narratives through reflection on the literature. Narrative conversation created a further hermeneutic circle, in which the children and I discussed and pondered the meaning of their experiences. Narrative conversation highlights the construction of identity through the retelling of experiences (Ricoeur, 1992). This method enabled the children to interpret their self-understanding through the stories they chose to share. Using these research approaches enabled a different knowledge of children to be produced, knowledge that has implications for occupational therapy research and practice.

Everyday Language

What *we* do is bring words back from their metaphysical to their everyday use.
(Wittgenstein, 1968, para. 116)

Rather than asking children about their understanding of the abstract concept of 'spirituality', I wished to explore the more meaningful embodied qualities they enacted, which I interpreted as spiritual qualities. I chose to interpret their stories and experiences through my questions and understandings, seeking to discover what these qualities meant to the children and how they were experienced (van Manen, 1990). I also sought out texts expressing the lived experience of spirituality, from poetry to plays,

autobiographies and novels. These texts resonated with and broadened my understanding of the research theme, how everyday spirituality may be expressed through narratives of self-identity.

As discussed in the previous chapter, the majority of the interdisciplinary literature on spirituality is general, focuses on adult spirituality, or children's spirituality in relation to their religious faiths. To 'capture the phenomenon' (Denzin, 2002) I used a deductive method to determine possible topics to elicit discussion of the embodiment of spiritual qualities in children. For example, the spiritual quality of belonging is embodied in connection with others (see Chapter 3, Spiritual qualities). Therefore, it may be experienced within friendships and family relationships (Appendix A).

I chose to talk with children within the middle childhood age group of 8 to 11 years. When compared with their younger or older peers these children had not been a focus of in-depth qualitative investigations (Greig & Taylor, 1999). As a clinician I had mainly worked with children under the age of 13, and in particular with those of primary school years. My clinical life experience had opened me to the words of children, and I wanted to draw on this knowledge in this study.

A convenience sample of four children (without disabilities) assisted me in expanding and refining the interview topics (Appendix B). These children worked through the topics with me, deciding which ones were appropriate, which were not, what language needed changing, and what topics had been left out that were important to ask. They also trialled and provided feedback on the relevance and enjoyment of possible accompanying activities. An experienced primary school teacher reviewed the topic language for general appropriateness for 8 to 11 year old children.

During the course of the participant conversations, topics were discarded and replaced. Some topics were omitted altogether (for example, What matters to you? Tell me about a regular day in your life?), because they did not open up conversation, contribute to its flow, or were too vague. Some topics were omitted for some children and topics added for other children. These changes depended on each child's cognitive abilities, emotional responses, non-verbal communication and the focus of their narratives. Interview topics evolved over the course of the participant conversations, based on the issues children raised within the context of their lives. This evolution enabled me to sustain a hermeneutic engagement with the children's narratives and the literature through reflection over the course of the research.

To develop my ability to converse with the children about their possible interests, I read the *Harry Potter* series (Rowling, 1997, 1998, 1999, 2000), Paul Jennings (1998) stories and *The Adventures of Captain Underpants* (Pilkey, 1997). Elvis² introduced me to Captain Underpants and to Paul Jennings' stories. I was able to converse knowledgeably and enthusiastically with the children who loved reading. Having been raised within the Catholic religion I was able to discuss bible stories, religious rituals and issues of faith with Cerberus and SSS007. My interest in music and movies also served me well, contributing to discussions with Michael Jackson and Cerberus. All of these interests served to strengthen and deepen my connection with the children, providing us both with the warmth of belonging through shared meaning, positioning the children as 'active knowers' rather than passive subjects.

² Each child selected his/her own pseudonym (see Appendix M for details). These pseudonyms will be used throughout the rest of the thesis.

My professional knowledge of impairments and the daily life challenges for children with disabilities meant that when children or their parents' spoke of issues related to impairment and disability I understood the language and issues they were discussing. For example, Michael Jackson had had surgery just before we met and his recovery program continued throughout our meetings. My understanding of what had happened to him in surgery and what he was undergoing in physiotherapy meant I could be sensitive to his physical needs. However, if I did not have knowledge of specific information related to a particular disability or intervention being discussed, I asked. For example, I was unsure about the impact of Bobby's continuing glaucoma and I asked questions of Bobby and his mother during the conversation his mother initiated.

Gaining Access

Children were accessed using purposeful sampling (Patton, 2005). This method was chosen so that I could extend the invitation to participate to as many children as possible, leaving the choice of whether to participate to the parents and children. The objective of this strategy was to access a diverse group of children with disabilities.

Ethical approval was initially gained through the University of Sydney Human Ethics Committee (Appendix C). Following this, eight major New South Wales agencies that provided services to children were approached, with six granting ethical approval or with a senior staff member authorising participation. Five facilitated access to participants; Spastic Centre of New South Wales, Royal Institute for Deaf and Blind Children, The Northcott Society, Sydney Children's Hospital (Randwick), and The Royal Blind Society (Appendix D). These agencies provide services to a wide range of children with disabilities either on an inpatient, outpatient, school or home visiting basis.

Three children were accessed through personal contacts. All participants lived in New South Wales or the Australian Capital Territory.

Once ethical or administrative approval had been gained, there was a downward process of contact to staff members who would distribute information to parents/children. Consequently I needed to gain approval at more than one level within each agency. I sent a letter to agency staff (Appendix E) to introduce myself and my research, made follow-up phone calls, and gave presentations in an effort to 'open out' the possibilities to whom information was sent. I then depended on the interest and commitment of staff members to send the initial information to families. Each agency representative determined the number of information packages they required. I provided a total of 146 packages.

The agencies did not send the information packages to all children to whom they had access. They sent the information to selected subsets they deemed appropriate. I do not know the rules they applied to determine the subset, nor do I know to what degree the gatekeeping was thoughtful, or to what extent it was arbitrarily determined by time, resources and the interest of the people in the agencies. I wanted all families with children within the age range to receive the information, and then for parents/children to self-select (Greig & Taylor, 1999). I felt that, potentially, children would participate who would not normally be considered by staff, and therefore wanted to circumvent this level of professional assumption (Morris, 2003; Morrow, 1999; Roberts, 2000). However, I was not privy to how the final decisions were made.

Initial contact. Parents and children received a letter requesting their participation (Appendix F). Included with this were information sheets for the parent

and child (Appendices G & H). The Royal Blind Society requested the children's information to be placed on tape or in large print. The Spastic Society of NSW (Metropolitan South & West Region) requested an adapted parent letter and information sheet for parents for whom English was a second language (Appendix I). Some agencies placed a covering letter with the information package or spoke with parents directly. The Northcott Society and the Royal Blind Society placed information in their parent newsletters. On receiving an expression of interest I made an initial phone call to the parent and set up a meeting time. In Deatherford's case his mother requested I send a letter to him to confirm our meeting time.

The initial meeting was organised to discuss the research project, the children's involvement, and to allow for questioning by the children and parents (Beresford, 1997). The children and parents then decided whether the children wished to take part in the research. This meeting was a time where I could be 'assessed' by the parents and children, and talk more fully about the details and aims of my research. During the initial meeting I paid close attention to the children's verbal and non-verbal responses. My purpose in doing so was to gain some idea of the children's level of interest and comfort, and the language I needed to use to communicate effectively.

I ensured the children understood they could withdraw at any time and acknowledged that if they chose not to be involved in the research, their right to refuse would be respected (Beresford, 1997). However, all children I met agreed to participate. They understood that if they didn't enjoy the process the first time we talked they could say "No" to further contact, either directly to me or through their parent. They were also informed they had the right to refuse to answer a question, and to turn off the tape

recorder and stop the interview at any time. These strategies were introduced so the children remained the 'final gatekeepers' of what they chose to share or not share with me (Davis, Watson & Cunningham-Burley, 2000). I wished to ethically respect their right to refuse. Elliot, SSS007, Lisa and Chontelle wished to begin straight away. These children had already decided they wanted to be involved and appeared to have received initial approval from their parents before we met. Before I had an opportunity to introduce the consent forms Keeta began telling me about her experiences in hospital, showing me her photo album from that time.

Issues of Respect

Consent. Initial consent was reached by the parents and children prior to returning the expression of interest. My subsequent phone call to parents, during which I answered any questions and explained the information further if requested, was another level of consent. Official informed consent by the children and parents was gained at the initial meeting through making the nature and purpose of the research transparent (Greig & Taylor, 1999; Kvale, 1996; Thompson, 1992). The nature and purpose of the study was presented in the required written format and I interpreted this in language the children and parents could understand (Beresford, 1997; Scott, 2000) (Appendices J & K), answering any additional questions.

In accordance with the University of Sydney guidelines, the children and parents were required to sign the consent forms prior to the children being interviewed (Koocher & Keith-Spiegel, 1994; Tymchuk, 1992). I often read the consent form with the children, adding explanations if they appeared necessary or if the children requested them. The children enjoyed the signing part of the process. Many of them had never had

the (usually adult) power of filling in a form and signing it. I also asked them to be the witness on the parent's consent form as an additional empowerment of their status as the important person in the project.

A separate consent form was used if the children and parents agreed to have selected visual media available for use in published materials and presentations (Appendix L). This form was completed at our final meeting and it was evident the children were comfortable with the process as they chose what pictures were 'public' or 'private', named the pictures and filled in the form. They were very clear about their decisions. I honoured them during this process by not challenging their decisions even though there were pictures I felt would have been very valuable for others to see.

Confidentiality. Disclosure of research data to the parent was discussed with the parents and children prior to the commencement of the interviews. If the children did not agree to their parent being able to access the information provided by them to me, then their parent needed to accept this choice. To ensure confidentiality within published information, identifying information was removed from the transcripts and no real names or identifying details have been used in this thesis. The ability to choose their own pseudonym was an empowering decision, as children chose a name only they and I would know. I told them it was their choice to share it with their parents or anyone else. Most chose to share the information with their parents. For 15 of the children the names they chose reflected something or someone of importance to them. For three of the children, the names 'just appeared'.

Dealing with disclosure. If children disclosed information during the interview where they appeared to be at risk, this information was to be made known to the relevant

parties as required by law (Beresford, 1997; Koocher & Keith-Spiegel, 1994). During reading and discussion of the consent form I often gave an example of what 'required by law' (see Appendix K, point 7) might mean, for example, their teacher locked them in a cupboard at lunchtime, an example that prompted smiles and giggles. I did not want the children to be afraid to speak, but I did make it clear to them that if they were being hurt in any way then it was my responsibility as an adult to help them and because of my position as a professional I had to tell someone who could help them. A requirement to report occurred on one occasion. When parents were notified, they were already aware of the incident.

Participants

The 18 children who chose to participate had a range of impairments, life circumstances and cultural backgrounds (Appendix M). Of the twelve boys and six girls; four children were 8 years old, six were 9 years old, seven were 10 years old, and one was 11 years old. Five children had cerebral palsy, five had a visual impairment, three had a hearing impairment, one had spinal muscular atrophy, one had attention deficit hyperactivity disorder (ADHD), one had had a frontal lobe atrioventricular mass, one had spina bifida, and one had had meningococcal disease.

The children's parents had ethnic backgrounds of Anglo Saxon, South American, Maltese, Greek, Italian and South Asian. The children lived in a range of family contexts; both parents, single parents, stepparents, with and without siblings. The socio-economic status of the parents ranged from wealthy to welfare, living in inner urban, suburban, country and rural areas. However, the focus of my research was on differentiating "between children in terms of their everyday experiences" (Davis et al.,

2000, p. 204) rather than on the basis of age, gender, social status, ethnicity, or category and severity of impairment. While not denying the influence of these factors, I chose to foreground the lived experience and identity of each of the children as it was mutually constituted within the contexts of their lives (Graue & Walsh, 1998).

Pilot Study

A pilot study with Elvis was conducted in 2001 to evaluate the appropriateness of the interview questions and additional approaches to explore the research questions with the group of children that were part of this study (Beresford, 1997). These pilot conversations highlighted the need for me to fully engage in the process. During these conversations I tried to keep myself 'removed' so that I did not influence what Elvis wanted to say, but this led to awkwardness on my part. My assessment was that it did not help Elvis to trust me if I was not prepared to share my self. My awkwardness with the role I thought I had to play as a researcher was highlighted for me when I transcribed and analysed the interviews.

The time between this set of conversations and the beginning of the rest of the interviews with the other children gave me an opportunity to reflect on my responses and his, and to decide that I did not wish to play the role of objective researcher but to become involved (Primeau, 2003). This decision proved to be a positive one, enabling greater connection and depth in my relationships with the other children through active interviewing (Dupuis, 1999). At the request of Elvis and his mother, Elvis' interviews were included in the analysis.

Timing

The formal in-depth interviews took place between March 2002 and December 2002. Meeting times were arranged at the parents and children's convenience (O'Kane, 2000) and were chosen by them to be either after school, on the weekends, in the early evenings, or in school holidays. The frequency of the meetings was also determined by parents and children, with 14 children being seen weekly or fortnightly. This seemed to 'suit' the process best in terms of developing trust and sustaining enthusiasm.

Cerberus, who was seen four times within one week, found it tiring and at times intrusive in his daily life. His mother commented on the family's general lack of time to themselves, "always going somewhere"; to medical or therapy appointments, to school, and visiting family. Keeta was seen three times within one week and I felt that more time was needed to develop a relationship of trust with her. Brett, however, was seen three times over three days and appeared to cope well with this time frame. I found it difficult to sustain a relationship of trust and being known with Cheezel who had long breaks between sessions, though he had an excellent memory of what we had discussed months previously.

Home Setting

As I had no prior relationship with the children, interviews within the children's home settings were preferred. I hoped to establish a different type of relationship from that of professional adult and child. I felt the children would have more relaxed relationships with female adults within their own home, for example, with aunts or grandmothers. Their homes were also the children's territories rather than mine. The children could be in an environment where they felt most comfortable, and where their

parents had the opportunity to be as much or as little involved as they wished (Nesbitt, 2000; O'Kane, 2000). Even if the parents and children chose not to have the parent present during the interviews there was still the opportunity for them to know that the other was close and able to be accessed if wished. I hoped this environment was the least disruptive for parents as it also allowed parents to continue with other tasks, for example, housework, caring for other children, and business commitments.

Within the family home, children were seen in the lounge room, dining room, kitchen, study or backyard. Two children were seen in their bedrooms, by their choice and with their parent's permission. If a parent and child chose another private location, the requirements of comfort and confidentiality were maintained. This only happened on one occasion with Lisa where I visited her at her grandparents' house as the family were staying with them for the weekend. Brett was seen at his school, in his classroom during recess and then in a staff office during class times.

Being in the children's homes and within their lifeworlds influenced our conversations in a myriad of ways. For Elvis, Rambo and SSS007 it was what had happened that day at school. For others it was what they were doing when I arrived: watching sport on TV (Bobby), playing with the dog (SSS007), playing on the computer (Max), playing with friends (Max, Nina and Keeta), having breakfast (Lisa), having dinner (Rambo and Michael Jackson), returning from school (Ian Welsh and Elliot). What was around us as we began talking influenced our conversations: books and drawings (Cerberus, SSS007), photos (Elvis, Chontelle and SSS007), animals (Bobby and Keeta), toys (Elliot) and computers (Max and Brett).

The flow and focus of our conversations was also influenced by what was happening around us: parents working (Elliot and Barney), parents leaving to collect other children (Elvis, Nina and Max), other siblings and their activities (Max, Elvis, Michael Jackson, Bobby and Rambo), younger siblings 'intruding' (Keeta, Lisa, Cerberus, Max, Cheezel, Rambo and Groovy Princess), and friends (Max, Nina and Rambo) and extended family's (Ian Welsh, Chontelle and Barney) visits. Our dialogue was also affected in some instances by what was going to happen when I left: doctors' appointments (Cerberus), sports activities (Max), meals and TV (for most of the children). Being within the children's homes enabled a greater insight into the relationships and contextual influences of these lifeworlds, adding to the richness of the data, my observations and reflections (Nesbitt, 2000).

Reciprocity

There seemed to be a 'window of opportunity' for access to the children within their family setting. Reflecting the parents' interest and commitment I was 'added to' the rhythm of family life and accepted into the family world. One parent acted as family organiser, which was reflected in negotiating meeting times around other family engagements and routines.

Primeau (2003) discussed the 'hook phenomenon' where the family has their own reasons for wanting to participate. I found this to be true for the parents in my study. There were certainly parents who felt it was important for children to be heard, that children with disabilities were never heard, and that it was important to be able to help other children through participation in research. For the parents of Groovy Princess and Keeta there was also the importance of their children having someone special to

spend time with and to talk with, and these children reiterated their parents' comments during our time together. But there was also a strong hook for six parents who wished to have help for their child or another child in their family through my role as an occupational therapist. Thus, there was a reciprocal nature to the relationship and one in which I was happy to participate; they were helping me and I was more than happy to help them in return.

I often had long conversations with parents at the initial meeting. I felt these were a necessary part of the gatekeeping process for parents, where they could make a considered decision on whether I was acceptable to them and to allow their child to participate. Parents also talked with me before and often after the interviews with their children, about ongoing issues with doctors, health professionals and schools. I was a sounding board about difficulties in accessing services, the parents' life in relation to their children, and their perspective of their children's lives through the impact of impairment and disability. These informal conversations gave me greater knowledge of the children's lives and their parents' influences on the children's identities and development of self. For example, Chontelle's and Michael Jackson's mothers shared a philosophy of children with disabilities being 'special'.

I did not seek out further information about the children from the parents or others due to my decision to respect the children and what they wanted to say. I wanted to avoid confirming or denying their perceptions through the adults in their lives. But I did reflect on the parents' conversations and considered what they had said in relation to what their children had shared with me. Their comments added to the picture of the children's lives and texture to my knowing of the children's lifeworlds. I was rarely

asked about the interviews themselves, perhaps because parents could either hear the conversation or the parts they overheard or participated in were 'acceptable' to them, or they respected their children's right to privacy. I think that the children's obvious enjoyment of the process and delight in my visits also supported the parents' trust in the process. The most common question was, "Did you get what you wanted"?

Shooting Portraits

My decision to capture the children's narratives through phenomenological (van Manen, 1990) and narrative approaches (Ricoeur, 1992; Riessman, 2002) created a reflective consideration of the dynamics of the research relationship. Combining these approaches developed a unique methodology, which I chose to enrich the exploratory nature of the research and to respect the children as active collaborators (Davis, 1998).

In the conversations with each child my purpose was to understand, not to direct. Thus I employed researcher techniques to allow this to happen, and used my self as part of the process. Because of the way I had decided to approach the interview process, there was a blending of my professional play and interaction skills with my personal conversational skills. There didn't seem to be a demarcation from one gaze to another (Lawlor, 2003a). Rather, the process was a blend of the two. I feel this was important as it would have been false for me to deny my professional self and this would have been seen as a falsehood by both the children and parents. My professional interest is what had led me to the research. This was stated in the information sheets they received and then reiterated by me at the initial meeting. I approached the children with the belief they had a lot to teach me and their thoughts and feelings were of great value. I was interested in them as human beings and approached them with openness. I wanted to get

to know them as valuable and interesting persons in their own right, not simply as research participants.

My preference was for only the children and me to be present during the interview, to ensure the children felt able to speak openly and without concern for the views or responses of significant others in their life, for example, parents or siblings (Garbarino & Scott, 1989; Mayall, 2000; Nesbitt, 2000; Scott, 2000; Thompson, 1992). However, whether or not parents were present for all or part of the time was the decision of the children and their parents (O'Kane, 2000). Some parents came and went; some stayed for the first interview only. Chontelle's mother attended all the interviews, acting as an informal interpreter for both of us, due to Chontelle's hearing impairment, and participated in all activities. Cerberus' mother attended two interviews, sometimes 'talked over' him, at other times prompting him with answers or information.

Rambo, Barney and Keeta had siblings present for all or part of the time. In Barney's situation her little sister was very helpful as she prompted Barney, gave additional information, and interpreted my language in a way that Barney could respond to. Nina had a neighbourhood friend present for the first part of three of the sessions. Although it was important for Nina to have her friend with her as this was their regular time together, she acknowledged she could speak more openly once her friend had left.

I acknowledge I could not erase the unequal power relationship that existed between the children and me with my position as an adult, health professional and researcher (Davis, 1998; Davis et al., 2000; Graue & Walsh, 1998; Morrow, 1999). Reflecting upon the potential impact of power issues, I tried to reduce its impact on our relationships through a number of strategies, including the use of a variety of research

techniques (Davis; Morrow). Whenever I could I sat on the floor with the children to create a less formal setting. I took care that my non-verbal language was open and accepting, I let them know they could make choices with the activities, did the activities with them, responded to their jokes and humour, and answered their questions honestly. I think most importantly I was willing to share my childhood and adulthood experiences with them, in particular the difficult experiences in social relationships and in trying to master skills.

I did not specifically ask the children about their impairment. However, if children raised the issue of the impact of their impairment on their lives I would discuss it further, as Deatherford and Brett did in our first conversations. I had learnt from Elvis that I needed to remain very aware of the children's non-verbal cues of discomfort or their desire not to continue with a more in-depth discussion and to respond respectfully to those cues and move on to another topic. The question that asked them how they were the same and different to other children, often brought a response directed towards their impairment as experienced through disability, even though the primary purpose of the question was to explore their perceptions of selfhood and sameness. However, for other participants this was not foregrounded.

Data collection occurred through audiotaped individual interviews. All of the children were shown how to start and stop the tape recorder, with the children stopping it at the end of the interview or with me asking whether it was time to turn it off. All of these strategies were employed to position the children and myself as co-constructors of the interview process, creating a space of negotiation and sharing (Davis et al., 2000). The strategies and techniques attempted to redefine the cultural power relations between

us. For all of the children I needed to remain reflexive towards their individual needs and responses (Morrow, 1999).

Use of the tape recorder produced a variety of responses in the children. Cheezel was very wary of it when we were talking about feelings in one conversation and asked me to stop taping. Elvis and Keeta remained conscious of its presence throughout our conversations. Rambo, Lisa and Bobby asked to listen to the tape during their sessions, so I rewound it and they listened intently to themselves. Lisa also spoke to the tape's 'audience' saying hello and commenting on what she was doing, as did Elliot by formally beginning and ending our interviews, and often announcing the progress of our games. Bobby played a trick on his older siblings when they returned home from school, getting them to speak and giggling about the fact that they did not know they were being taped. Each time we met, Elliot, Groovy Princess and SSS007 made sure the microphone was positioned properly and Elliot often spoke into the microphone with his mouth only a few inches away. The rest of the children ignored the tape recorder once we entered into the first conversation.

Journal notes, which included the home setting, dynamics between family members, and my thoughts and feelings about what had occurred during and surrounding the interviews, were made as part of the interview notes for each child. However, observation techniques were not used as a formal data collection method. I could at best only be a peripheral observer of the children's interaction with others and their world (Adler & Adler, 1994). Thus the primary method of gaining data was through narrative conversations. The journal notes provided a further means of reflection (Alvesson & Skoldberg, 2000; Primeau, 2003).

A mutual journey. The multiple interviews (three- five sessions from ½ hour – 2 hours duration) with each child developed rapport and enabled the development of in-depth discussions (Beresford, 1997; Greig & Taylor, 1999; Scott, 2000). The length and final number of interview sessions was determined by the children, how immersed they were in what we were doing, how easily they tired during each interview and whether they chose to negotiate further time(s). The length of the sessions also depended on the additional activities we engaged in, where these wove our conversations together, gave times of simply being with each other and enabled a sharing greater than that of researcher and participant.

Indirect questioning and discussion were utilised as they were not as confronting as direct questioning (Greig & Taylor, 1999; van Manen, 1990). The use of semi structured interviews allowed the children to influence the direction and pace of the interviewing in partnership with me (Alderson, 1993; Mayall, 2000). The unequal power relationship between us (D'Alessio, 1990) was therefore more balanced than it would have been through structured interviewing (Graue & Walsh, 1998; Morrow, 1999). Active interviewing (Dupuis, 1999) enhanced the process through developing trust and rapport.

I needed to reach a comprehensive understanding of the information shared by the children (Beresford, 1997) and I did this by rephrasing, reflecting, asking for further clarification and presenting possible options ending my comments with "or . . ." The reflexive intervention of my comments, questions and ponderings on what they shared with me 'generated the data' (Gibb, 2002) by creating a conversation. I was heartened when children disagreed with my comments as they were telling me what they were

saying was their opinion, not mine given back to me so that I would be pleased. I encouraged narratives by using questions as prompts for further details, picking up on leads and openings (Engel, 1995). However, reflecting on the interviews as they progressed made me aware of how much more I had to learn. This ongoing reflection and my continued learning helped to ensure their voices were being elicited rather than my assumptions of their voices (Davis, 1998; Davis et al., 2000). I was listening attentively to their perceptions and interpretations of their lived experience.

For transparency, an overview of the interview content was made available to the parents, which provided an outline of the topics discussed with the children (Beresford, 1997) (Appendix B). Sharing this overview gave an opportunity for parents to discuss any words that needed to be altered to match their child's level of understanding or life experience. I had structured the topic guide so that (theoretically) each conversation, including the adjunct activities, would last no longer than an hour. My clinical experience with creating '1 hour' therapy sessions enabled me to 'feel' the time and end the conversations within this hour, unless children wished it to continue and parents were agreeable. Clinical experience assisted me in sustaining the children's interest through the use of activities and redirection, and it also helped me to be aware of signs of tiredness and disinterest. These sessions with the children made me aware of how much I needed to learn about each child, that I still made many mistakes, and had bad days where my responsiveness was blurred (Lawlor, 2003a). I became aware of the need for time to reflect on each of the children, to consider them and what they needed from me.

The initial interview focused on eliciting information regarding the lifeworld, interests, likes and dislikes of the children. These topics were based on an initial interview form presented by Cronin (1996). The use of non-invasive questions promoted conversation and provided a means of establishing rapport (Beresford, 1997; Nesbitt, 2000). The information gained allowed me to develop a general picture of the children's lives, thereby enabling the placement of the children's sense of self in the context of their life and an awareness of possible influences on their lives (Bronfenbrenner, 1979; D'Alessio, 1990; Graue & Walsh, 1998) without physical intrusion (Wagner, 1999). These topics enabled levels of connection through shared interests and experiences, and promoted empathy and mutual understanding. I was able to gain further insight into the children's expressive and receptive language and abstract thought levels, attention span, use of humour and an awareness of how the children used and responded to non-verbal communication. This was important in terms of the following interviews, which were asking the children to express deeper and more intimate thoughts and feelings.

I hadn't expected, in the first interview, the distress and discomfort that resulted from asking about friendships. The topic was an emotional issue for some of the children; Lisa cried, Keeta avoided answering and Cerberus appeared to be deliberately vague when answering. Subsequent interviews developed topics in depth, again through the development of deeper levels of understanding and rapport as the interviews progressed (Kvale, 1996). The topics related to present and future issues were adapted from Oaklander (1988). The order of topics was adapted to each child's lead. As the interviews progressed, issues of isolation, rejection and bullying were voiced by many of the children, reflecting the difficulties some children had with discussing friendships.

Closing off. I needed to remain aware of when children were 'closing off' topics because they did not wish to talk about them further. Elvis' strategy was to end with saying 'anyway' and lapse into silence while turning his eyes away from mine. Cerberus employed a similar strategy, using "so" tapering into silence. Rambo and Barney finalised discussions with, "And that's it." Cheezel was uncomfortable with talking about sadness, asking me to turn off the tape recorder. At the end of this conversation I asked him about the topics for our next conversation (i.e. talking about hope, trust, courage and joy) checking to see whether he would feel comfortable with them. His only comment was to mention, "When people break your trust". I was very uncertain whether something had happened to him that was emotionally painful or whether he was referring to me, or both.

In our final conversation, Cheezel was happy to talk about courage when I removed it from the context of his life, asking him to tell me about someone else he thought was brave. But he avoided responding to my conversation on the other topics, using the lack of his hearing aids and the creative activities as a means of 'politely' avoiding the topics without having to directly tell me he didn't wish to discuss them. Most of the children adopted Cheezel's strategy when they wished to share no more on a particular topic, refocusing the conversation onto our shared activity or onto a topic such as a TV programme. They took themselves into safer emotional waters and creatively protected their right to privacy.

Clarification. In order to clarify my understanding of their thoughts and feelings I employed a number of strategies with the children. During the interviews I checked with the children about comments they had made by restating what they had said and

posing it as a question. I also went back over topics during the following interview, after having listened to the tape of the previous interview. For example, with Elliot, I explored his thoughts on bullying and the importance of non-violence.

I found it extremely helpful when children were clear about whether I had understood them. When talking with me about trust and friendship, Elvis patiently took me through what he meant until he knew I understood "100%". Deatherford was tactful when disagreeing with my suggestion about the 'feel' of a photograph he had taken. He told me, "Well, it depends how you put it . . . you could say that could represent that, or you could say that it was just [moving]." Although my interpretation could be one way of looking at it, for him it was simply a photo of the wind in the trees.

I found it very positive when children disagreed with or corrected my interpretation of their discussions. Cerberus and Chontelle were vocal in disagreeing with me, seemingly due to the open relationships they had with their mothers and their level of comfort in disagreeing with them. Their mothers were involved in the interviews, creating a context for the ability to disagree with me, someone who was outside of this close relationship. Other children, for example, Bobby, SSS007, Barney, Nina and Rambo, told me when they didn't understand a question, "I don't get you" (Bobby) or when the question was difficult for them to answer, "I know what it [hope] means but I don't know how to explain it" (Nina).

Lisa was the seventh child I saw and following her request I provided children with copies of the interview tapes. I made these copies between sessions so I could give the copy of the previous session to each child when we next met. I sent most copies of the final interviews by mail. Eleven children received copies, with two children

choosing not to take up the offer. Some children, like Lisa, Elliot, Groovy Princess and SSS007 listened to their tapes. Others, like Rambo, simply wanted to have them. The tape copies provided an important way for the children to comment on the conversations if they wished. Simply being able to hear their own voice was important for most of them. Although I did ask them whether they had listened to their tapes, the usual response was a nod and a smile. I now wish I had capitalised on this opportunity for clarification by actively seeking comments and asking further questions.

Creative Media

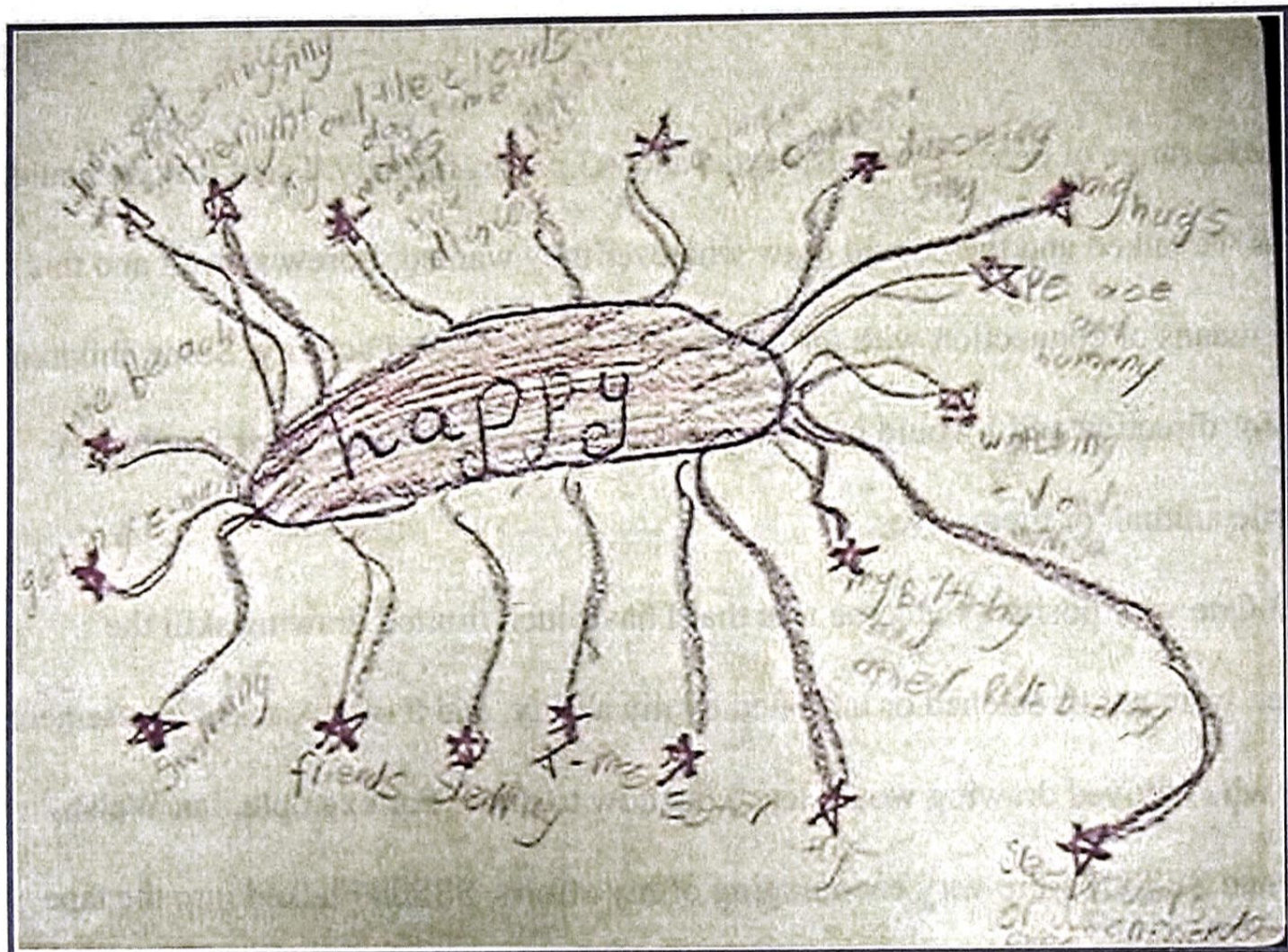
Provision of a range of creative options acknowledged and respected the diversity of the children (Christensen & James, 2000) and therefore their possible preferences for expressive materials (Oaklander, 1988). My decision to use creative media within the interviews was fourfold. Firstly, I wanted the children to have a pleasurable experience, which in childhood is often found in artistic expression. Secondly, I wanted to avoid the situation where the children might feel scrutinised if we were only talking and not 'doing'. Thirdly, it was a way of connecting with the children through shared activities and hopefully reduced feelings of vulnerability. Fourthly, it encouraged the children to engage more fully in the consideration and discussion of the topics. What the children and I ended up doing within each conversation was driven by their interest and creativity, and ultimately the meaning each activity had for them.

Drawing. I used drawing to encourage narrative and discussion (Alderson, 1993; Beresford, 1997; Greig & Taylor, 1999; Oaklander, 1988; O'Kane, 2000; van Manen, 1990) and to encourage the children to reflectively engage in the process (Bendelow & Brady, 2002). Drawing was introduced from the beginning of the first session, where I

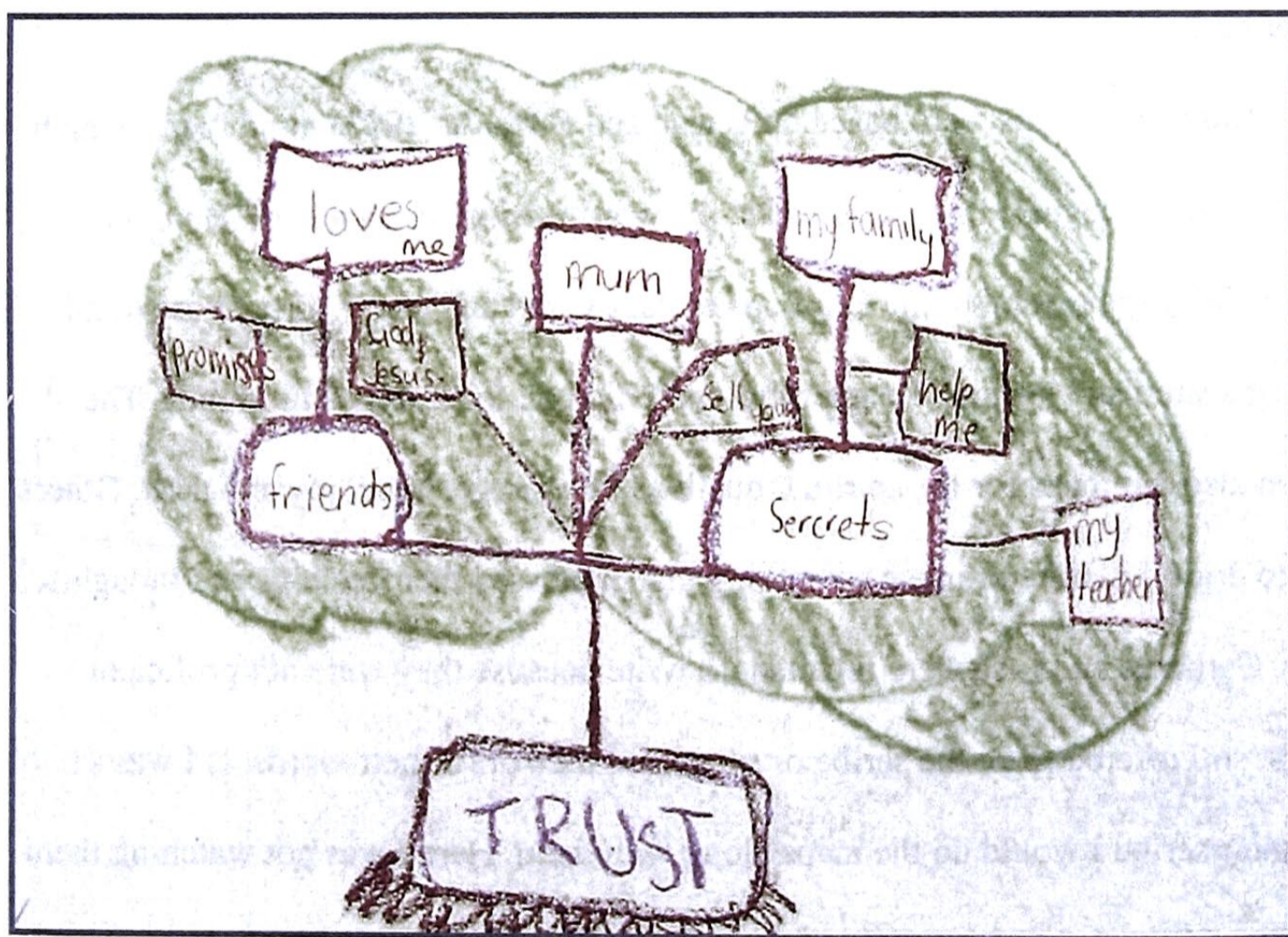
provided a range of pencils, pastels, textas and A3 paper. Initially, I said that we could draw as we talked and they could draw whatever they wanted. I drew as well and this gave a means of connection with the children through a shared activity. Some children asked for direction and I would make suggestions, such as drawing their family, pet, favourite animal, or themselves.

One very positive outcome was that I have such limited drawing skill the children were not threatened or inhibited by my ability, and it often caused amusement. Those who enjoyed drawing would teach me how to draw. For example, Ian Welsh, Keeta and SSS007 were very encouraging of my efforts. SSS007 talked into the tape recorder giving drawing tips. Those who felt they couldn't draw well were encouraged by how much better they were than I was, and we would discuss our wish that we were better artists.

Maps. The maps were based on Buzan and Buzan's (1993) mind maps, which some children recognised as 'word webs' or 'word worms' from school. Here the children did maps related to the emotions of happy, sad and angry. Lisa chose to do maps for scared and jealous. Deatherford and I did one for family and friends. The children also did maps for the spiritual qualities of courage, hope, joy and trust. Others chose to draw a picture or make something that expressed their feelings and thoughts. Bobby, Cerberus and Lisa were reluctant to write because they were not proficient spellers, so I offered to be the scribe or suggested they draw their words. If I wasn't being their scribe I would do the maps along with them. Here I was not watching them with a 'researcher/adult gaze' while they were working and we could talk as we wrote and drew, thus facilitating ideas and memories.



Drawing 1: Groovy Princess' Happy Map



Drawing 2: Chontelle's Trust Tree

Doing the maps along with the children was also a way of 'giving permission' as I tried to be very honest about what I wrote. We often swapped ideas. For example, one of us would write something on our maps and the other would make an exclamation of recognition, then adding it to our own map. When discussing the maps I would ask them whether they wanted to 'go first' or whether I should. I hoped these strategies would reduce any vulnerability they may be feeling in expressing themselves if I was prepared to do the same, thereby facilitating trust and a sense of equality (Lawlor, 2003a). Elliot, Brett and Deatherford preferred to simply talk about their thoughts.

Ian Welsh created detailed feeling maps with many 'branches', turning our shared activity into a friendly competition (as did SSS007 with our faith maps) of who would do the most branches and finish first. His happy map was centred on the page as an oval creature drawn in red and blue, with a rounded tail, round eyes and a smile, and four pairs of legs. He placed the people and things that made him happy at the end of each of the legs and branched from there. His angry map was a similar creature, this time all in black, with angry eyes and mouth, a pointy tail and again with four pairs of legs.

Groovy Princess' maps for happy, angry and sad were similarly creatively detailed (Drawing 1). Chontelle chose to draw a trust tree with the apples in the tree being where she placed her definitions of trust and those she trusted (Drawing 2). Her feeling map of joy was a bright yellow sun with its rays (branches) streaming from behind a blue cloud. Cerberus drew representations of religious stories to explore his perceptions of courage and hope.

Pictures. A calendar of Australian birds and animals (Krutop, 2001) and a selection of books; *Animalia* (Base, 1986) and *The Eleventh Hour* (Base, 1997) were introduced to facilitate discussion of the topic (Beresford, 1997; Greig & Taylor, 1999; Oaklander, 1988), "If you could be an animal, which one would you be and why"? Again, I participated and explained my choice. This topic was chosen to explore qualities the children saw as desirable and important to possess through the ability to change physical shape, a shape outside the adult and human world, through the language of metaphor (Lakoff & Johnson, 1980).

Art/craft activities. New activities were added up to the end of the interview phase, reflecting the differing interests of the children. These included; play doh, clay, Lego™, pipe cleaners, craft kits, origami, cards, checkers, chess and dominoes. For those children with specific visual, physical or cognitive impairments I adapted these activities so they could play, drawing upon my occupational therapy skills.

All activities provided further opportunities for connection through shared enjoyment and in my case shared learning. For example, Nina, Keeta and Groovy Princess involved themselves with the craft materials, Ian Welsh, Keeta, SSS007 and Lisa with drawing, Bobby with checkers, and Brett with checkers and chess. The activities promoted a situation where conversation could occur in a non-threatening way, where it was part of the flow of what we were doing rather than the focus. I chose activities I felt would not interfere with our conversational flow.

However, with Cheezel, Bobby, Rambo and Michael Jackson the activities sometimes 'took over' the session and we needed to negotiate when the activities would happen and when conversation would happen, so that both our desires could be met

within the time we spent together. The use of board games became a negative influence with Elliot as he became distressed when he didn't win. In his case a strict interview approach was the best option, one he suggested for the final interview. The use of activities extended the length of the interviews but was an important component of building an open and trusting relationship with each child.

Photographs. My decision to provide cameras for the children was prompted by an article by Clark (1999) who had used 'autodriven interviews' with children, which "allowed children to visually show and tell aspects of their lives that were important to them" (p.40). The children were offered the option of using a disposable camera to take pictures of people, places, events or things that were of importance to them. These photos, which I either developed or reimbursed the parents for developing, were used to facilitate discussion of the children's lifeworlds (Clark). As the total contact with each child occurred over the period of weeks or months (and in Brett's case a few days), the photos assisted me to understand the children's lifeworlds without intrusion (Fine & Sandstrom, 1988; Mayall, 2000; Wagner, 1999).

Photos also promoted the possibility of self-reflection of, and continued engagement with topics by the children between the interviews (Clark, 1999; Glesne, 1999; Nesbitt, 2000). An Information Statement (Photographs) (Appendix N) was required by the University of Sydney Human Ethics Committee to be given by the children to any person they wished to photograph. This was to be accompanied by a Photograph Consent Form (Appendix O).

I saw the photos of 11 of the 18 children. Children chose to retain their photographs and I respected their decision. All of the children were enthusiastic about

getting a camera to use and most had never had one of their own before. The power of having one's own camera to capture the moments that matter without being too closely controlled by an adult was evident in their pleasure and consideration of the photographs they chose to take. Deatherford finished his before I left the first session and Rambo by the second session. SSS007 was a keen photographer and Michael Jackson's grandfather was a professional photographer. However, Ian Welsh, Bobby and Max kept forgetting to use the camera. Keeta, Groovy Princess and Lisa misplaced the camera or the photos. If the children had not finished taking their photos within the window of contact, then further access was often lost.

Next week? Cool!

During the course of the interviews mothers and children often stated they (the children) were excited to be seeing me again. When I thanked SSS007 at the end of our first meeting he replied by stating, "I should thank you." He wanted to know when I would be coming again, and was pleased it was the following week, "Next week? Cool"! Groovy Princess stated it was, "... good to be part of something at last." Three of the children expressed their happiness in having 'someone to play with'. More than one parent commented they were pleased their children were receiving 'one-on-one attention'. Chontelle's mother commented it was important for children to be heard. Rambo's mother concurred with her, remarking it was important children had a say, to which Rambo agreed. He told me adults thought they knew how children felt, with the implication in his voice that this was not true.

There were no drop-outs once the interviews had begun and a number of the children wanted me to come every week (and wanted to know why I couldn't), wanted

to negotiate further times or expressed sadness when I left. Groovy Princess presented me with a butterfly cake, which we shared with her mother and siblings, and a gift of a blue witch. Keeta and her mother invited me for dinner following our sessions on three occasions. As I left for the last time Keeta gave me a hug and wanted to know if 'someone else from my committee' would be coming to see her. Elliot was agitated when I left his last session. Elvis cried. Nina told me, "I'm happy that I'm with you now", but she was sad I was not coming to see her anymore. As she came to the car with me to say goodbye she gave me a 'friendship handshake'. Rambo succinctly stated, "That sucks" when I confirmed that the following week would be my last visit.

Post Interviews

I felt it was important for the children to determine when contact ended and thus not perpetuate the unequal power relationship of adult/child, therapist/client, researcher/subject. I wished to respect them as people with whom I had shared an important and special time. Thus I gave my email address to those who asked or I agreed to visit again those who requested it. This was seen by colleagues as being a potential difficulty. However, I believed there was a research issue in being intensely in children's lives, talking with them intimately and then severing the contact because 'I got what I wanted'. This did not seem to respect the children, but rather treated them as commodities to be used. My decision proved correct as the children who wanted ongoing contact chose their own time to let the relationship end.

I sent all the children a thank you card of their favourite animal or other significant picture, reflecting my listening and remembering. I also sent them a

Certificate of Appreciation (Appendix P), an outcome of comments made by Chontelle's mother.

The children's artwork was returned by the end of 2002. Although the consent form detailed that I would return artwork at the end of my analysis, the children's disappointment in 'losing' their artwork prompted me to revise this decision. When I was able to access a digital camera I placed their artwork on CD and was thus able to return their original work fairly promptly. The children and their parents were happy with this decision, granting their permission for me to retain a digital copy of their work.

Weaving

The adult listener must sometimes weave together the narrative that seems to be buried in the flow of a child's play and conversation . . .
(Engel, 1995, p. 20)

Analysis was conducted using phenomenological (van Manen, 1990) and narrative methods (Riessman, 2002). These methods enabled a reflective weaving together of the children's narratives, unfolding their construction of identity and the meanings of spirituality through story and metaphor (Lakoff & Johnson, 1980; Ricoeur, 1992).

Data from the interviews were transcribed verbatim from the audiotapes. I was able to transcribe 15 of the interviews but due to ill health I needed to engage transcribing services. However, I edited all 76 transcripts, which gave me a further opportunity for familiarisation by listening again to the tapes and reading the transcripts making initial analysis notes as I went, contributing to descriptive accuracy (Maxwell, 2002; Miles & Huberman, 1994). There were two interviews where taping was either extremely poor or had not occurred, in both Cerebrus' and Michael Jackson's fourth

interviews, which were 'lost' to the analysis. The five professional presentations I gave during the course of the research provided important opportunities for initial case summaries and further reflection.

Crystallisation of the data (Janesick, 2000) was achieved through the inclusion of, and reflection on, the interview tapes and transcripts, photographs, drawings and artwork, and the parents' conversations. Some of the children showed me other things they had made, other photos and drawings, and introduced me to their pets. Elvis, Barney, Chontelle and SSS007 showed me school photos, pointing out their friends and those they didn't like. Keeta showed me the photo album of her hospital experience pointing out the hospital staff she had particularly liked. She took me to meet her quails and showed me the grave of her cockatiel that had died a few days before we met. Groovy Princess took me to meet her rabbits and showed me her bedroom, a magical room full of stars, artwork and memories. Michael Jackson showed me a TV ad in which he and his friends had starring roles.

Bracketing enabled me to clarify and set aside my expectations of the information the children chose to share (Garbarino & Scott, 1989). Prior to commencing the literature review I wrote about my beliefs of childhood, disability, spirituality, and the therapeutic relationship. Through draft writing of the literature review before the interview phase of the research began, I made explicit my personal and professional views on spirituality, childhood, and the construction of identity and disability (Graue & Walsh, 1998). Doing this helped me to clarify what I was seeking to understand and how it resonated with clinical and academic works. I also bracketed my beliefs by presenting my ideas to other professionals.

I believe bracketing (Garbarino & Scott, 1989) was invaluable in assisting me to enter into the interviews with as value-less an identity as possible. In addition, I believe I achieved a deeper understanding and acceptance of how to be open to the beliefs and values of the children. Bracketing through listening to and reflecting on the interview tapes and my interview notes, assisted in keeping me focused on what the children needed to say or not say, rather than my need to hear particular themes within their narratives.

Talking with these children gave me the unique opportunity to spend time with children with disabilities without having to 'do' anything as an occupational therapist: no splints, wheelchairs, home modifications, or adapted pencils. No therapy agenda. I learnt much about myself over this time: my nervousness as a beginning qualitative researcher (rather than an expert clinician); my discomfort with the role of 'receiving' rather than 'giving' (my entrenched role as helper); my tendency to interrupt; my concerns about probing too deeply when a topic was emotionally difficult for children to discuss (not respecting their strength in being able to cope with their sadness); and my ability to get distracted by our mutual pleasure in the accompanying activities.

Ongoing reflection of my feelings and responses enhanced my understanding of the influence of my self on the interview process (Alvesson & Skoldberg, 2000). Each of the children called in different ways to my self and spirituality. Spiritual qualities of the children that 'stood out' were those of trust, purpose, courage, creativity, compassion and joy; qualities they employed in their lifeworlds and extended to me while I was with them.

I also learnt much while I was away from the children. I contracted a debilitating neurological condition just prior to the pilot interviews, which continued for four years. I have had my own lived experience of being 'disabled' and needing to draw on my spiritual qualities in ways I had never envisaged. I experienced my own sense of Erikson's (1963) 'industry vs. inferiority', isolation and misunderstanding, not belonging in the 'real' world, being treated as 'different' by others, and having to deeply rethink what gave my life meaning. I took a year's sick leave following completion of the interviews and during that year I edited the interview transcripts. This time meant I could immerse myself in the children's narratives, reflecting on their truths and searching my own.

I approached the analysis with a preliminary conceptual framework based on the literature (see Chapter 3, *The Practice of Spirit*). During the formal data analysis stage I manually coded each transcript twice to ensure the consistency of my coding before reducing the transcript information by writing up individual case summaries (Miles & Huberman, 1994). Coding took the form recommended by van Manen (1990) where each set of transcripts was read as a whole, then selectively read and finally read in a detailed manner in order to "isolate thematic statements" (p. 92). Initially, data were coded within content categories, for example, fighting with a sibling. Subsidiary themes emerged, for example, connection. Meta-themes related to spiritual qualities were then identified, for example, belonging. These levels of coding and theme generation conceptually mirrored the path I had taken in determining the interview topics (Appendix Q). For example, if a participant discussed a friend demonstrating kindness

this was initially coded as friendship/kindness, then coded as connection/empathy, then coded as belonging/compassion.

The within-case analysis gave an opportunity for further familiarity with the data and theme generation (Eisenhardt, 2002). These summaries included transcript excerpts with transcript/page codes identifying their location. This enabled a hermeneutic approach to the summaries and transcripts as I moved back and forth between them, seeking to develop my understanding (Alvesson & Skoldberg, 2000). The summaries were thematically approached in the same way as the transcripts, as I sought to clarify the links between the children's narratives and the emerging conceptual framework.

Summary narratives were grouped under the main themes of spiritual qualities identified in the literature (see Chapter 3, Spiritual qualities) or under subsidiary themes. Thematic statements and their link with spiritual themes were refined and further developed during the course of the analysis (van Manen, 1990). When constructing these summaries I made initial connections with other children's narratives and with the literature. The first four summaries were reviewed by my supervisors, providing interpretive and theoretical validity (Maxwell, 2002).

Lisa, Deatherford, Chontelle and Michael Jackson were approached in 2004 to gain clarification and verification of my interpretation of their transcripts (Alderson, 1993; Beresford, 1997; Glesne, 1999), giving a measure of descriptive validity (Maxwell, 2002). The children read their case summaries and provided feedback. Deatherford, Chontelle and Michael Jackson gave approval of my summaries, not requesting any changes or deletions. Lisa and I engaged in a hermeneutic conversation (van Manen, 1990) as she provided me with detailed feedback, adding comments on the

experiences she had shared and discussing my interpretations. Her feedback was added to her summary before further analysis (Appendix R).

These children read their summaries nearly 2 years after their interviews. My approach to them could be assumed to be invalid, as they may not have remembered what they had said. However, the children either remembered their experiences or were reminded by the summaries. Lisa's feedback highlighted for me her ability to remember her life and her discussions with me in detail. Another potential concern was the length of the summaries and the theoretical language I included. Here again, Lisa was able to work her way through the manuscript. She seriously considered whether she agreed with my interpretations and discussed words with which she was unfamiliar. For example, she insightfully commented on the meaning of alterity, "[other people] Treat you like you're somebody." Due to resource and health constraints I was unable to approach all the children and do not claim these four children were representative of the group.

Cross-case analysis (Eisenhardt, 2002) was facilitated by using *NVivo 2.0* (QSR International, 2002). I initially coded the 18 summaries under individual spiritual qualities. However, as with the development of the topics, I found the embodiment of spiritual qualities was intimately interwoven. I decided to recode the children's summaries under the contexts of their lives; home, school and community, which reflected "the situated nature of children's lives" (Graue & Walsh, 1998). I created a further node for their speaking of themselves. Within these nodes I teased out the relationships the children had with others, the meaning of activities, and their experiences of selfhood and sameness within these relations; which allowed me to retain the interweaving of spiritual qualities (Bazeley & Richards, 2000).

Cross-case analysis (Eisenhardt, 2002) enabled me to search for similarities and differences within the children's experiences, their ways of responding to these experiences, and their feelings and thoughts generated by the experiences they chose to share. Refining of the themes continued during the writing up of the analysis. How the children utilised spiritual qualities in their everyday lives and how their embodiment influenced identity, resilience and vulnerability became a further hermeneutic circle at this level of the analysis. This circle included movement between the children's narratives, generated themes, and the literature.

Writing the analysis was an interpretation; a weaving of the children's narratives and theory, my view and their voices, reflecting the interweaving of spiritual qualities within their relations with others. Thus, within the contexts of the narratives they shared there is a linking of their voices and mine, and the voices they heard and understood of others. Where the active voices of myself and others are included in children's narratives I have placed them in italic text. Explanatory comments and the replacement of identifying information have been placed within square brackets.

The stories the children narrated are rich with the embodiment of spiritual qualities, qualities they drew from themselves, they evoked in others and others offered to them. My writing attempts to reflect their voices and spiritual qualities in ways that retain the children's meanings, their interpretations of themselves and their lives (Riessman, 2002). To weave together the children's narratives and reflect upon my experiences while being with them I needed to listen closely, to become immersed in their tapes, transcripts and artwork, to let their voices tell me about themselves.

The Research Relationship

Research has much in common with *re-spect* – in which we also look again, look more fully and appreciatively at who or what is before us, honoring that person, thing, or event for what it is in itself and for what we may learn from this interaction.

(Braud & Anderson, 1998, p. 245)

This research utilised hermeneutic phenomenology (van Manen, 1990) and narrative conversation (Ricoeur, 1992) to explore and analyse the embodiment and utilisation of spiritual qualities in the lives of the 18 children. The reflective act of hermeneutic phenomenology and the relational act of narrative conversation interconnect with the relation of being with children in therapeutic contexts where the stories of their lives are spoken into being. Thus, the methodology employed in this research contributes to the development of research approaches with children with disabilities as well as to considerations of practice. The method positioned children as active and knowledgeable participants in the stories told of their lives and considered their agency within the context of practice. The research included the development of tools and assessment of outcomes in which they were seen as capable of offering their views (Alderson, 1993) and in which their voices were heard.

The exploration required an engagement of my self, a willingness to enter both the narrative and home worlds of the children. I needed to respect what they wished to share and what they considered to be private. The variety of creative media helped to create a space of connection and sharing, one in which we could develop our relationship. Utilising diverse methods with a core of narrative conversation enabled different levels of communication to occur between us (Morrow, 1999). The children's

responses to the topics and the activities reflected their uniqueness, their desires and needs, and called upon my responsiveness to their way of being.

Many factors influenced what the children chose to tell me: our shared acculturation; their trust in and openness with others; the sense of trust and openness I expressed towards them; their understandings and expectations of what would happen with what they told me; the identity they wished to present, to themselves, to me and to the world of adult listeners; what was meaningful in their life when the conversations occurred, whether moments within that conversation, that specific day, or moments of greater time; their relational experiences with other adults in their lives; and very importantly the openings and leads I touched or missed (Engels, 1995). Although I endeavoured to create a space that enabled their narratives to be heard and accepted with respect, where they were the creators of their own truths, our relations were always bound by the contextual 'truths' of their being in the world.

How can occupational therapists create an emergence of a child's self within any space in which we meet him or her? Within relationships with children connecting with their sense of self and what they need from us is paramount. Connecting respectfully, allowing children to sense safety, not to be overwhelmed or to feel controlled, to let them lead, setting the tone and pace of the interaction will enable the children to sustain their sense of agency (Piper, 1999; Rogers, 1951, 1961). Here, the physical context becomes irrelevant, removed, as a space is created within the context that while it remains within, is also outside its space and temporality. Within this space children can create what they need it to be, enabling their self to emerge in safety (Bollnow, 1989b). Ultimately, it is a child's self that we wish to see and to connect with

meaningfully, not a child's identity as proscribed by the world in which he or she and we live.

When we are in a child's temporality it carries with it respect for his or her way of being and the way in which he or she is choosing to become (Rogers, 1961). Our therapeutic power is quietened and we must be patient (Bollnow, 1989a). This is not always easy as our acculturated professional self keeps wanting to resurface and take charge, giving prescriptive choices in the name of empowerment (Maslow, 1999). But when we succeed in remaining quiet, the relationship that develops with a child is one of mutual respect and enjoyment. There is a deeper pleasure that comes from being *with*, from a sense that this relationship will be a journey of discovery and sharing. For a little while we are his or her companion, establishing a meaning-full relationship with a child within his or her world.

Chapter 5: Composing the Self

Self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. It is *the self as reflexively understood by the person in terms of his or her biography*.

(Giddens, 1991, p.53)

Occupational therapy is concerned with identity building formed through engagement in occupation (Christiansen, 1999). If we wish to position children as active creators of their identities, then we need to reposition ourselves from the stance of 'expert' (Hanna & Rodger, 2002; Rogers, 1980) to one that seeks to understand how children see themselves (Moustakas, 1959; Sturgess, Rodger & Ozanne, 2002). Within this refocusing, we need to consider how and why children construct their own identities, thereby enabling children to engage in occupations that hold meaning for them. From this altered perspective, we can co-construct the engagement children seek without restricting their occupational desires (Egan & Townsend, 2005).

Childhood is a time of learning the self and the self of others (James, 1993). Children speak the self into being through an understanding of the self as separate from and entwined with others (Merleau-Ponty, 1964). In contrast, adult-centric views of children's identities often predominate where identity is proscribed through categorical definitions of childhood and disability (Jenks, 1996). However, children's understandings of identity are fluid and relational, situated within their reflexive understandings of biography. These understandings reaffirm their uniqueness of self and may challenge traditional theories of childhood (James, 1993; James et al., 1998).

Children are active agents who create their identities through stories that are embodied and reflexive (Merleau-Ponty, 1964; Seigel, 1999). In working *with* children

it is important for us to ask for and listen to these stories so our knowing of children is positioned within their understandings of themselves (Mattingly, 1998; Mattingly & Garro, 2000). We may more clearly understand the spiritual qualities children find within themselves and how they express the embodiment of these qualities within the everyday.

This chapter explores the embodiment of spiritual qualities through the children's stories of self. Their stories of origin, perceptions of selfhood and sameness, and perceptions of their qualities relate their understandings of being. Through their stories of otherness and desires for becoming, they express their desires for themselves.

Stories of Origin

Two children told narratives of the time of their birth, stories they heard from their parents and reinterpreted within their life narrative. Bobby wrote a story about himself, which he read to me, "When I born I wasn't good, but my parents and God look and care about what was happening. And from that they, I been brave and trusting, trusting doctors and I am praying . . . to be ok, one day, but for the moment I am so happy who I am and I, do a lot of things with my family, my dog and some friends." Bobby's origin story encompassed purpose, courage, hope and trust. These qualities were drawn from his relations with others and evoked within himself as meaning and resilience. The story reflected an alterity of being, of being cared for by others, of continuing to hope that one day he could be physically 'ok'. He constructed his sense of self through his story and by being valued in his relationships with others; his parents, doctors, God, friends and his dog (an intersubjective understanding of self).

For Elliot, being who he was and the life he knew held much meaning for him. When we spoke of 'special things' that happened in his life, he replied, "Some of the special things are, some of the special things are I live in a great home, and I'm alive still, and I survived that operation [blood transfusion] when I was born." A little later in the same conversation he mentioned it again, "Well, I don't think, well I don't think some things that wouldn't, probably wouldn't very rarely happen in kids lives would like when like I was born, very rare kids who were born with vision impairment. They rarely survive it. And I'm very lucky to have survived it. . . . The Lord gave me a little special gift and he gave me a great life." He was thankful for many things in his life. In his origin story, he attributed his survival and part of his agency to God's grace and purpose. Elliot's response was that life was to be lived, enjoyed and treasured.

There is evidence in these stories of adult interpretations the children have internalised. Elliot used the phrases 'vision impairment' and 'The Lord', both of which resonate adult viewpoints and language. The children's stories of origin, perhaps mediated by adult stories, reflect each child's understanding of self, and the self in relation with the world. The stories remain 'present' (*sensu* Game, 1991) by giving purpose to the children's ongoing experiences. For Elliot, his impairment was a gift, for Bobby it was a time of courage and being cared for. For both children their impairment was enfolded within their lives. However, each of them transformed their origin story from one of medical knowledge to one of personal meaning, a transformation that involved a reinterpretation of stories (Miner, 1997). These children shaped their responses to the negotiations of the self in part by understanding the becoming of their disability, expressed in these stories.

An Alterity of Being

Many of the children spoke of their impairment, its impact on their life and their sense of identity, woven in with the hope for their impairment to be cured. These narratives arose from asking the children about their wishes, their dreams and daydreams, their desires for the future, how they were the same and different to other children, and from drawing hope maps or speaking about the meaning of hope.

Bobby, Brett, Elliot, Elvis and Cerberus all spoke of a hope or wish for their impairment to be ameliorated. Bobby's wish was for his eyes, "To be better" and on his hope map he had placed, "[Better] eyes . . . No more eye drops, be tall, be healthy." Like Bobby and Brett, Elliot wished for "full vision", as Elvis did for "not being disabled", Rambo for being able to walk, "and, never go to physio again", and Cerberus being free of his wheelchair when he went to heaven. Cerberus' hope drawing showed his wheelchair with himself walking away from it. His drawing was very poignant and he was a little shy about my reaction to it. He perhaps wondered whether I thought he was foolish and would laugh at him, as he was sharing a very personal hope I might not respect or understand. All of these children expressed desires reflecting compassion for the self. For all, this meant leaving behind the restrictive aspects of the physical self. They knew it might never happen, but this did not reduce their hope.

'Unobtainable' aspirations may be considered unrealistic, and therefore to be discouraged. However, in the lives of these children, there were no misunderstandings about the probabilities of recovery. Rather, the aspirations reflected their resilience through their ability to hold different stories of their future selves. For these reasons, such hopes needed to be respected as part of their story of themselves.

Elvis and I talked about daydreams. He, like Cerberus, used an electric wheelchair. He told me his dreams of what he would do when he grew up, then in a very quiet voice he said, "Well I have one more, dreaming about . . . just not being disabled, but we can't stop it, that's bad, but anyway." This was a very private dream he was careful about sharing with me. Although this dream was one he thought would never happen, it was important for him as, "I would dream about it at night time, all the things I could do in my daydream", like run and walk, ". . . it feels like I'm just a normal person." In these dreams, he did what he daydreamed about. He could run and walk, like any other boy. In them, he transcended the experience of his physical self and fulfilled the hope of his daytime dreaming. He renegotiated his identity through imagining a different physical self; an alterity of being that within his dreams brought him joy. This dreamt-of alterity was beyond his control, evident in the resignation of his voice as he spoke of not being able to 'stop' being disabled.

Elvis was concerned with being alone, with being physically disconnected from others, as he felt he needed others to survive, "If I was in the middle of, the desert or something, I couldn't survive, I would just die. Because, I couldn't help myself, because I can't do anything to help myself. Because no-one would be there to help me." He was anxious because aloneness (loneliness) threatened his very existence (Giddens, 1991; Moustakas, 1961). Anxiety was strong in his voice and was reflected in his concern over not having control over his physical self, having to give it to others to survive (Maslow, 1999). For Elvis, this physical aspect of self overwhelmed his knowing of self, creating an enmeshed identity (Minuchin, 1974) rather than a separate agentic view of self. His dreaming enabled freedom from dependence on others, and an ability to construct his

own reality. As for the children who expressed hope of an altered physicality, Elvis' dreaming was a manifestation of that hope.

Not all children spoke of a desire to change their physical selves. For some, narratives were focused on their knowing of themselves through awareness of their difference. At the same time they were focused on the sameness of their identity as a capable and valuable person, sharing the interests of their peers. Ian Welsh expressed his views over two of our conversations. He had a visual impairment and while we drew he would ask me to confirm the identity of colours in the pencils he selected. He didn't appear concerned or embarrassed that he needed to ask for assistance nor did he hide his need for help, blending his requests with the flow of our interaction. I gained a sense that for him his impairment was only a small (incidental) part of who he was. He confirmed my feeling, "Not to me it doesn't [matter he was different from the other children he knew]. It doesn't need to." Who he was physically didn't need to change the way he perceived and understood himself and his relation to the world, and the world's relation to him.

Ian Welsh knew his physical self as 'different', "Because I've got more problems than anyone else. Eyesight and stuff like that", but considered his identity and lifestyle as the same, "I don't go into like disabled [sports] comps or anything I just stick with normal people, I do all normal things." In saying this, he was entering into the social construction of disability, an otherness rather than an alterity of being. He was aware of the social construction but contributed to it through his comments. He resisted positioning himself as 'other' through his consciousness of his selfhood and his sameness of 'normal' participation (Ricoeur, 1992). Thus he moved between imposed

and desired positions, speaking of his ambivalence towards the social construction of his identity and that which he saw within himself (Tenberken & Kronenberg, 2005).

Like Ian Welsh, Groovy Princess wanted her selfhood to be known and sought the selfhood in others that lay beyond the mask of physical sameness. Groovy Princess wore a prosthesis on her left leg. She had just received a vivid purple one with outlines of flowers in lighter purple and white, telling me her previous one, "If, later on I can show you my other one. That's what, it's pretty good my other one. It was purple sparkles." These two prostheses vibrantly celebrated her physical being and expressed her selfhood. Her prosthesis was an embodied expression of self (Iwakuma, 2002), a part of her emotional being and thus part of her identity, "And maybe later too I'm hoping that you can take a picture with it off and when it's on. Just, and even if you put part of my story in the magazine, I'd like you to put the picture in there. So at least people can see what I look like and like even writing, like because I don't care what I look like or what my friends look like, only what they feel, like what they're like in their heart. That's what mum's always telling me, so I'm trying to stay with that."

Groovy Princess' experiences in relating to others position her physical self as lesser and she continued to resist this positioning by holding on to her mother's wisdom, seeking to internalise her mother's words and beliefs (Bronfenbrenner, 1979). She knew her self as the same as others in her heart, wanted the complexity of her self to be known rather than only her physical self, and wanted to know others in the same way. There was a tension between the celebration of her difference through her brightly coloured prostheses, where impairment was beauty (Snyder & Mitchell, 2001), and her striving to focus on the feelings of others. Like Ian Welsh, a dissonance was constituted from the

experiences of her social world and her desire to be known for herself.

Keeta, Lisa and Bobby expressed issues of sameness within difference in relation to physical characteristics. When I asked Keeta how she was the same and different to others, she replied, "With my [absence of] fingers and my scars and different eyes and different hair and different skin." She was conscious of the differences her physical body displayed as a result of meningococcal disease but was also conscious of 'general' traits, and like Lisa, of sameness, "Like we've both got bodies, we've both got heads, we've both got eyes." She understood herself within her sameness, although her physical being was in some ways different, its essentialness was the same (Snyder & Mitchell, 2001). These differences were minor and her greater physical self expressed the completeness of her identity.

In our first conversation, Bobby told me there were four other children in his class who wore glasses. In our fourth conversation, when we were talking about being the same and different, he told me he had checked how many children in his class wore glasses, "I checked, there was more. Like six. If I count myself there would be seven. The teacher has glasses. And all the teachers have glasses." He found a sameness within difference that made him very excited and pleased, a sameness that enabled the reconstitution of belonging (Ricoeur, 1992).

Other children spoke of sameness and difference within friendships. When I asked Nina how she was the same and different to her friend, she replied "We both like art." They both liked swimming, her friend was not a Christian but Nina didn't know what she believed. She knew her friend, "She likes sleeping with her mum and I don't." When I asked SSS007 how he was the same and how he was different to other children,

he began with a statement of uniqueness, "Well one thing I've got to say, every single person is different." For him, "Oh, I'm the same that I believe in Jesus and so does my friend. . . . And I'm different in the ways that I'm not a bully like some kids are. . . . And [Friend] and me like the same games, playing games, like fishing and playing games." These children experienced sameness and selfhood through interests, ethics and religious beliefs, the everydayness of life.

Deatherford spoke of an otherness of self through his sensations and behaviour. When he didn't take his medication for ADHD he sometimes experienced 'weirdness', "Well, if, I forget, I feel like, weird sometimes, like I'm going to burst out or something. *Do you get really jittery and stuff, you know like you want to bounce around or?* Sometimes, it's like I get that feeling when I, I don't take the proper dose. I mean when, I like when, I've only got I'm supposed to have one and I've only got half left, so, it makes me, it depends how, how, how I've done it, if I haven't taken a proper dose it makes me feel all bouncy but if I don't take anything at all, I feel like I'm going to explode. Well when I take the proper dose, when I take the proper dose it feels all fine and you know. *You feel better? Yeah. And if you don't, if you haven't taken anything and you get that explode feeling, is that a good feeling, too?* No. Cause when you, if you explode you feel like, I feel like I'm going it, it like, like rage."

Thus, the feelings Deatherford had on medication were preferable to those he had off it. In both cases he was not in control of himself, but feeling hypnotised was better than feeling like he may explode into a rage. The feeling of 'explosion' didn't scare him, "Well no, just feels all tingly inside." Rather the possible consequences concerned him. He expressed his consciousness of changes in his experienced self and

the wisdom of knowing the benefits to be gained by these changes. He accepted the difference of his medicated self because he preferred this lived experience as it enabled him to engage with the world in purposeful ways.

Although the children in this study identified themselves as the same as other children, they were very aware of their differences. This included the limitations these differences placed on their lives, and the often negative responses of others to their physical, sensory or neurological difference. Their relationships with others influenced how they positioned themselves within their alterity of being. However, in these narratives their alterity was more strongly influenced by their understandings of themselves. Their reflection on their impairment spoke of its embodiment within their relational being in the world (Merleau-Ponty, 1962). The children's narratives highlight the need to understand the experience of impairment as part of the construction of identity (Morris, 1991). Their individual experiences and reflections created differing understandings of self (Shakespeare, 1996).

For most of the children their impairment was not an aspect to be pitied, it was not their whole self but an aspect of their physical self. They were not simply a 'disabled body' (Grosz, 1994), an object of difference. All of them retained hope for a positive change in their physical self, not simply for the sameness, but for the freedom this would bring. This change would enhance their ability to engage with the world, enabling other ways of being, and for many it would cease the endless round of medical interventions (see Chapter 8, Medical & Disability Services).

Being Themselves

I often asked the children to describe themselves or we would talk of qualities it

was important to have in order to engage with life's joys and challenges. We spoke of personal qualities when discussing spiritual qualities. These conversations helped me to understand their emotional self, the ways in which they responded to the world from within their being.

Brett, Ian Welsh, Keeta and Barney spoke of being themselves and believing in themselves. 'Being himself' seemed to be a 'given' for Brett, "That's just, part of life I guess, being able to accept who you are and stuff, yeah. I wouldn't change for someone else." He had a strong sense of identity and of the value of his being, which was supported by his religious faith (see Chapter 8, Religious Faith). He considered himself to be, "Oh well, I'd probably just say, kind, brave, loving person, I suppose. Considerate." He spoke through awareness of his spiritual qualities of courage, love and compassion. Brett said, "Probably, just, what's just, heart and soul, that I've got to have, I suppose." Within himself he found a core that gave him emotional strength and supported his being in the world. Ian Welsh echoed Brett's faith in himself (see An Alterity of Being, above). Keeta thought it was, "Very important to believe in yourself." When I asked Barney who else she liked in her class she replied, "I love myself." For these children, faith in and love for the self created a belief in the self as valuable, fostering resilience when challenged by others or by experiences.

Common narratives spoke of consciousness of the qualities the children possessed, expressed through their relationships with self and others. I asked Elliot what qualities it would be good for someone to have, "You want the characters that they have, the gifts that they have? *Yeah, or gifts yeah. And so they could have courage and trust and hope and forgiveness* [qualities he had spoken of previously]. *What other gifts*

would it be good for a person to have do you think? Would help them in their lives?

Being able to walk on two feet. Being able to be kind to anyone. Being able to help.

And being able to do things you want to do in your life. All I believe in is just, I'm just happy with the things I have." These were 'gifts' of physical ability, empathy, caring, agency, and a will to be, speaking of the quality of consciousness within the self entwined with expression of the self. He was happy with his life as it was lived and known, a life that embraced the other and the self.

Groovy Princess described herself as, "I'd say chatter box. I am a bit, like I'm anxious to see people and things. Like just stuff like that. . . . I like singing and dancing and yeah. . . . I like giving things and being with my friends. *And you're thoughtful.* Mm hmm. That's kind of like caring for others." She was anxious to connect with others through talking and being with them. She knew herself as giving and caring, possessing a generosity of spirit and showing expressions of love through the gifts she gave, including that of her self. She was aware of the joy and creativity she experienced through artistic expression. The children's narratives reflected awareness of the self as agentic, resilient and vulnerable, displaying understandings of the self in relation to their own needs and the needs of others.

When I asked Rambo to describe himself he said, "Man that is so hard [a hard question]. I can't walk, and I'm disabled." So I rephrased my question. "What am I like as a person? I'm normal. Funny sometimes. Enthusiastic. And that's it." Initially he positioned himself as other through physical difference but described his identity as 'normal'. He thought he was kind, sometimes generous, sometimes thoughtful, and always brave. He spoke of his identity with honesty and wisdom because he didn't

position himself as 'always' funny or generous or thoughtful. He understood he could embody these characteristics but did not always choose to do so.

In our last conversation I asked Rambo, "*Talking about, being brave and coping and trusting people* [qualities he had identified as part of himself] *and, I want to know whether, you reckon, you were, born that way, or whether you learnt how to be that way or? Learnt how to be that way.*" His learning came through being in the world (Merleau-Ponty, 1962) where trust, courage and faith were called forth and enacted within his relations with the world, becoming a known part of his identity. His comments also reflected his consciousness of the effort needed to be in the world, through enacting qualities needed for engagement with others.

Elvis spoke of his desires for expression through narratives of physical action destructive to others. When we talked about hope, Elvis related it to, "You hope something and it doesn't come true, like a wish." He told me a story about an unfulfilled hope in relation to a Christmas present he didn't receive, a story of not being heard. His unfulfilled hope led to disappointment and anger, "I was really angry." He then went on to tell me a story about someone else in the same situation, "Just pretend I was somebody else, I said I got a present that I really didn't like and I was angry . . . so angry that I, I . . . burnt down the school." Anger became destruction and then punishment, "And they suspend me from the school" and he reminded me "It's not me, it's somebody else." At first, "I was really, really calm about it" but then the anger grew and so did the destruction, ". . . then I started getting really, really, really, really, angry, so I burnt down the house . . . and after that I burnt down the whole wide world."

His story was an extreme expression of anger, an ability to wreak revenge for not

being listened to, not having his wishes noticed. Within this story he had the power to inflict harm when his hopes were not realised. However, his story can also be understood as a creative strategy enabling him to express the depth and breadth of his anger at not being heard by others. He was able to express himself without direct harm to others or to himself. Elvis' story of hope flowed into his story of joy. He told me he would feel joy, "If I burnt down the classroom, and the whole wide world, and I burnt down the house." He would experience joy through retaliation for injustices perpetrated against him. His actions gave him a sense of power, of making others suffer for the suffering they had caused; an agency of retribution. His storied self contrasted strongly with his feelings of physical dependency, enabling a different sense of self to be experienced and known. Although Elvis appeared to feel unable to 'be himself' in his daily life, through narrative, he was able to express the self he desired.

The children's narratives of being themselves evoked spiritual qualities they clearly felt within themselves. These qualities of love, trust, joy, courage and hope were embodied within their responsiveness to others and caring for themselves, and their continuing engagement in life (Zukav, 1989). The children's understandings of their identities were reflective, a sharing of their human *being*, one in which they trusted themselves (Dalai Lama, 1996; Moore, 2002). The similarities and uniqueness of the children hummed through their discourses, where each voice held the request to be heard for and by itself.

Courage and fear. All of the children in this study were asked directly about courage; what it meant to them, whether they thought they had courage. They were asked to tell a story about themselves, someone else or one they had heard. Often they

placed courage within a hero concept (Campbell, 1949), as an otherness of self they may have experienced but did not feel within themselves as an everyday quality (Tillich, 1952). Courage was seen as an absence of fear rather than a part of their being they drew upon to enact their lives.

Some children considered themselves to be brave and positioned this within their everyday lives. Brett spoke through a certainty of self, "Well I got put in courage didn't I? For, cause we went on a Confirmation camp and you got put in groups, and me and my two best friends got put in courage." The directness of the look in his eyes and the firmness in his voice gave me the sense that he felt the decision was appropriate and my initial question had an obvious answer and didn't really need to be asked.

For Groovy Princess being brave meant, "Standing up to yourself. *To yourself or for yourself?* Both. And like just being true to yourself, not being like you're just someone who's doing nothing and a really dull kind of person. And someone who always has their head down, like you're not that person, you're kind of strong. And like instead of being a [door]mat you should be like standing up for yourself." Her sentiments were echoed by Ian Welsh when he spoke of what he considered to be 'good' qualities in others, "Ah, being cool, I mean like sticking up for yourself and all that." These children used metaphors (Lakoff & Johnson, 1980; Potter & Wetherell, 1987) to create images of physical strength and honour, in turn creating emotional strength. Courage was embodied in their everyday lives through respecting, expressing and defending the self (Tillich, 1952).

On his courage map, Bobby placed, "Ride scooter, wear glasses, going shopping alone, play soccer." He explained the need for courage while riding his bike, "When it's

dark it's hard, when it's light it's easy." Wearing his glasses was a similar experience, "The same thing. It's hard, in the night time." Courage was needed to wear his glasses at school, especially when he was called names. Bobby also told me he needed courage to wear them at home, though he didn't explain why, and when he went to Boys Brigade where other children, "Say 'Big eyes' and say 'Four eyes'." He drew on his courage when being teased and when engaging in activities he found difficult to do alone because of his visual impairment. Through courage he retained his belief in himself.

Bobby also did a map for brave. I asked him what the difference was between courage and brave, "Brave is means you're brave. Brave means you're not scared, you're brave. Courage means you're not scared either. You're brave. I don't know." He became confused as he tried to explain. He had placed different things on his brave map, "Swimming, ask questions to strangers . . . operations. I'm brave at the hospital." We tried again to sort out why they were different concepts for him, but the feelings they engendered in him were the same. They both made him feel happy, strong and 'good' inside. Courage and bravery lived in the everyday of negotiating his lifeworld, although with a foundation of 'not being scared'.

When Deatherford and I talked about courage, he told me how he dealt with doing something 'scary', "Just try not to think about what, what might happen, in that place. Or you could try to, try to not think about, what's going to happen inside, in that place, and try not to . . . make yourself want to run away from it, try to keep, just try to make yourself not, not just turn away. Or a good way to make yourself not do it is by closing your eyes, and you just walk into it and see how things go." He had developed his own creative strategies of not dwelling on what might happen and staying with the

immediacy of the experience. He found courage within risk-taking creating a transformation of self, which enabled him to continue to engage in 'scary' activities he wanted or needed to do.

In our next conversation Deatherford told me he was sometimes brave, "It just matters, it just matters what's happened, and what's happening, and, and what's, what's, and what's doing something like that, or like, what's, what's, making me feel a little bit scared, but trying not to, like, like trying like not, not, its something that's scary but, its not really working, to try and do something, or find a [way not to be scared]." Again, he spoke of courage that could be experienced and drawn upon within anxious moments, used to help conquer fear and to continue to engage with life and its demands. Sometimes he could be brave and do what needed to be done, ". . . and sometimes the other way round . . . cause it's just too, big or something." Here he acknowledged his courage sometimes failed and he was overwhelmed. In these times he needed to draw on the courage of another.

I asked Keeta whether she thought she was a brave person, "Maybe, maybe not. Maybe, maybe not", but wouldn't elaborate further. Her answer perhaps reflecting the dissonance between her knowing of her self and the expectations of social codes of behaviour as I asked how she would know someone was brave, "When they're not crying. . . . They never cry. Always get a lolly when they be good." Courage was conditional and rewarded, not an intrinsic knowing but one conferred by others through acceptable behaviour. Lisa also voiced uncertainty about whether she considered herself to be brave and talked about not crying being an act of courage, "That's a bit brave. I, it's hard to hold tears [back]." She talked about the girl in *Ghost Horse* (Simner, 1996)

who held back her tears when *Star* "disappeared forever". The girl in the novel showed courage when faced with the loss of her beloved horse. This was an experience Lisa had also known. For Lisa and Keeta, not showing fear or sadness through 'not crying' was their understanding of the lived experience of courage. Courage that reflected the internalisation of social mores, leaving these girls wondering whether they were brave because of the feelings they experienced.

Resonating with his love of reading and of Roald Dahl's stories, Cheezel considered the character *Matilda* (Dahl, 1988) to be brave, "Well she was really smart and she was brave against the, the big you know transport [Miss Trunchbull, the headmistress of Crunchem Hall]." *Matilda* is the story of a young girl who is intelligent, good at maths and loves reading, strong parallels with Cheezel's self. She used her intelligence to assert her agency with adults in her life who were behaving badly towards her and those she cared about. She is also sensitive and polite, qualities Cheezel himself possessed. Meaning was being made as he entered and was entered by the story (Becker, 1992). Although Cheezel saw *Matilda* as brave, negotiating the difficulties of her daily life, he didn't consider himself to be brave because of his fears. Courage for Cheezel, like Cerberus, seemed to equate with an absence of fear, "I'm really scared. Especially at night. I mean the dark." This was a fear he shared with Cerberus and other children.

When I talked with Cheezel about the sorts of fears of the dark other children, including myself, may have had, he was very pragmatic, "Sharks under the bed? I wouldn't be scared of that. The sharks wouldn't be alive. If the sharks were, if the sharks were under the bed for all that time like for a few days, they'd be dead. Because

they'd have hardly any air to breathe." He reflected the pragmatism of Cerberus, who dismissed sharks under the bed as he had cupboards under his bed and thus the sharks wouldn't fit, telling me instead, "Well, sometimes my door is pretty good, but I see like wolves with blood coming out from their teeth, like that's the only thing I don't like, is wolves". For Cerberus, these fears had come into being through the reading of *The Three Little Pigs* (Galdone, 1987) and *Little Red Riding Hood* (Perrault, 1967). His night-time fears of safety arose from the innocence of fairy tales.

Night-time fears of being attacked are common to many children (Mooney, Graziano & Katz, 1985). In Cerberus' situation they were made all the more threatening because he couldn't physically protect himself. Cerberus shared with me an animated and intense narrative about nightmares and wolves. His narrative spoke of his vulnerability in the 'face' of attack, of his rich imagination in which animals that would kill came alive, fears that haunted him at night. Dreams became reality within the experiencing of the dream, where Cerberus suffered the "inferno" of life (Campbell, 1968, p.335). An inferno present in his everyday life of being a child with a severe physical impairment.

For Cerberus, courage meant, "Not being scared." On his courage map he drew a picture of Hercules astride a foe, and one of St Michael fighting the Devil. In both pictures he drew them much larger than their foes and standing on top of them. Strong and heroic figures that triumphed over evil, confronted their fears and banished them. Courage placed and understood within heroic acts rather than the everyday of being himself. Within these drawings was his expression of re-interpreting himself as someone brave and physically masterful, of his desire for triumph over his fears (Campbell,

1949).

Fear of the dark had also been an issue in Keeta's life, "... but then a couple of weeks ago, or months ago, well actually a year ago, well I like the dark because I can't get to sleep in the light. . . . I only keep the door a little bit open but I generally try and. Because sometimes it gets really dark. I'm not scared but I've got flashing lights in my [room], and sometimes I get nightmares that there are monsters coming. And I get really bad nightmares. And if you don't tell they come true. So that's why I tell every nightmare. Every dream I have I've got to tell." She had found a way of transforming her fear of the dark through her need of it to sleep and of releasing her fear through speaking of it. These creative strategies enabled her to sleep and to dream without her fears becoming real in daylight hours.

Lisa had also found a way of transforming her fear of the dark, "Some people are scared of the dark. I'm not scared of the dark. I used to be, but now I'm not scared anymore." Now, "I like the dark sometimes . . ." because "I can see nocturnal animals in the dark." Thus the dark could be a friend, not always the foe it was for Cheezel and Cerberus, as it brought gifts of animals not seen in the brightness of daylight hours. But the dark did become threatening to Lisa at times, "If something scary happens and then I go upstairs and it's dark, I get scared, yeah." Being alone, vulnerable and overwhelmed, where her fear was greater than courage embodied within darkness and dreams. Fears she shared with Bobby and Groovy Princess.

Lisa's primary fear was being alone and the only thing that helped her, "Being not alone and that's the only thing. It's hard to describe, that's all that helps." Courage was found in the presence of another, which resonated with Elvis' desert narrative (see

An Alterity of Being, above). Lisa chose to do a map for 'scared'. Her discussion included, "And ghost stories . . . so just write. Write scary books. So they make me scared. Cause it's about ghosts, well not about ghosts just . . . sometimes it's not scary. *Cause you like the ghost, you like the Star books and they're not scary, are they?* No, but the person that was following them and stuff was a man, she was scared and then but she found out it was the owner, they died in a fire together, and the boy's name was Michael." Even though Lisa loved the ghost horse, the boy following *Star* and the girl was a scary character until Lisa knew who he was. Lisa identified with the girl's sense of love and belonging with her horse and her fear of being chased by the unknown. Like Cerberus, this story had come alive for her. This story was woven in with her own fears and dreams, where fantasy and reality intersected as she created her understandings of self.

The children's sharing of their narratives of courage and fear caused me to reflect on how the concept of courage is portrayed. In children's literature and the values of adults it is often an absence of fear in the face of great danger (Campbell, 1949). Courage is not often spoken into being by adults as an ontological concept, where fear can be present hand-in hand with courage drawn upon and experienced within the small acts of everyday life (Tillich, 1952). The children's understandings of courage as a concept and thus as an embodied quality were reflected in the particular narratives they chose to share.

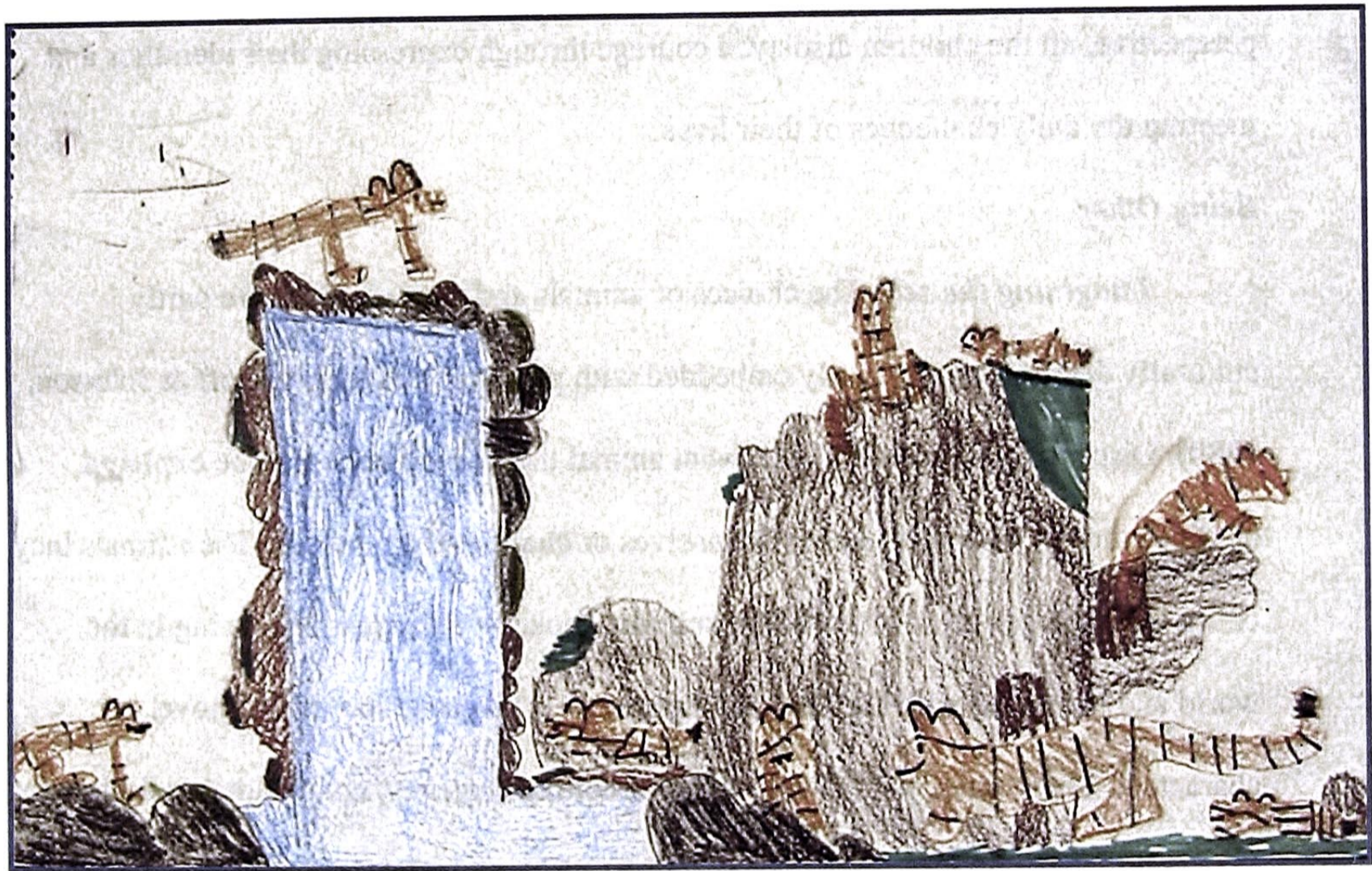
Their narratives also spoke of the children's creativity in finding ways to transcend their fears. Brett, Rambo, Groovy Princess, Bobby, Deatherford and Ian Welsh understood courage as an everyday quality, one which they clearly saw within

themselves and drew upon in meeting the challenges to the expression of their identities. How these children negotiated their lives was influenced by their courage, which enabled them to continue to engage in life, to express their desires and needs. From my perspective, all the children displayed courage through expressing their identities and meeting the daily challenges of their lives.

Being Other

Imagining the self. The choices of animals and their qualities are partly culturally determined and partly embedded with personal meaning (Lakoff & Johnson, 1980). Discussing with the children what animal they would choose to be explored qualities they experienced within themselves or qualities they desired. The animals they chose were images of an otherness of self that spoke of a transcendent being in the world and resonated with the hero qualities of their favourite movie and novel characters. These metaphors of self spoke of courage, agency, and children's desires for expression and creativity. Like their narratives of being themselves these images spoke of their selfhood and sameness in relation to others.

Asking Cheezel to imagine what sort of animal he would be raised issues of agency and safety, "I would be a little lice, a tick. . . . So then nobody can see me and then kill me. And then, but ticks don't last very long. OK, a turtle. I can, I can live for about one hundred and some, one hundred and something years. . . . I think it's one hundred and eight. I'd be a monkey. . . . To be really cheeky and I could do really amazing stunts on the thing and I could, and, oh yeah, I wouldn't have to do work and, the zoo keepers would feed me and. Wow, yeah, and then I could smack my mum's bum." Initially, he chose an animal that was unseen and therefore not vulnerable. He



Drawing 3: Lisa's 'Tigers and Water Fountain'

then chose longevity, but also an animal with a protective shell. Finally, he chose an animal that would be cared for, and cheeky and clever. Through these choices he seemed to be expressing his desire for agency and freedom within a safe world.

Max chose a tiger, "Because they're, they're fast and, powerful, and fierce." Like Ian Welsh he chose an animal with agency and the ability to defend the self. Ian Welsh told me that when he got angry, "I go 'roar'." He voiced the lion's response to danger, to warding off a threat or staking his territory, complementing his choice of a lion when asked to choose which animal he would be. Lions were powerful and in charge, "Lions eat other people." They were dominant rather than victims. When we were looking at Cerberus' books and discussing sea animals, he commented, "Shark, great white, that my favourite." Although I didn't ask him why, I wondered whether he responded to its fearlessness and physical strength. Lisa's love of and identification with animals spilt over into her daydreams, "Sometimes I daydream about me being an animal and sometimes I wish I was an animal. I mainly dream that I was, I'm a horse cause that's my favourite animal. Yeah, running really fast. Sometimes I wish I was a tiger, or a lion. *And why would you like to be one of them? . . . they live in the wild. Really do anything they want*" (Drawing 3). These and other children chose animals that were free, had no human rules to live by, lived in unfettered realms, could run fast and were powerful, being in their body.

As we looked at and named the animals in *Animalia* (Base, 1986) I asked SSS007 what animal he would choose, "I would be, oh, I would be a kangaroo. Cause they are very strong", but as we progressed through the book he changed his mind, "Oh, no a lion. A lion, a lion, a lion! Yeah, I'd be a lion." He chose another animal that was

strong, and fearless, and could scare away others. Good qualities for dealing with bullies, which was an issue in his life (see Chapter 7, When people are mean). As a lion or kangaroo he wouldn't be scared, "I wouldn't because they, the, scare the things away. Cause they're brave, they've got courage. They're friendly, well I would be. *Yeah, you would be wouldn't you. I wouldn't be scared of you if you were a lion.* But what if you never knew it was me? *Then I'd be very, very careful, until I knew.* Get straight into the lions den. *No!* Then I would tell all the other ones not to do anything." SSS007 spoke of animals of strength and bravery that could care for themselves when threatened, but in his imagining could also protect others.

Moments of being other were also raised by Cerberus and Ian Welsh when drawing. Transcendence wove with Cerberus' love of animals when he drew a picture of his three wishes. He wanted to be a wizard, one that could perform magic with animals, to fly on a unicorn and to own a pet lioness. His wishes spoke of an alterity of being and connection with the animals he loved. Although for most of the children wishes and hope were similar, Cerberus positioned them separately, with wishes being fanciful and hope being very seriously related to his religious faith beliefs.

Ian Welsh spoke of transformation and an otherness of self as he drew a picture in our second conversation, "I'm going to do a version of my robot. Robot house. One, two, up on these houses. They're like, it's a spy house, like with cameras there. There you put your hand on that to know how to get in. That's like your own code. The car jumps off there, does a u-turn, and drives off into the air. Aeroplane, cloud, helicopter, chimney turning half rocket, garage that can walk and talk, if you can see it they're his legs, eyes, garage in his mouth, satellites. All turning into these two robots. See that

thing, that thing can go poof, go away and it can turn into like a little dagger with two fingers or it can just go 'poom', and nothing there and it's like a hammer. Two done. They lift, they come down into there and his wings fall down and he's got a cape on. That's a drill. I'm gonna draw big one." The story of Ian Welsh's robot house was of a character that could become and do many things, who was adaptable and could look after itself, who had agency and the power to transform itself. His character was a robot of creativity embodied through adaptability, resourcefulness and ingeniousness (Sheldrake, 1989). The strength of Ian Welsh's lived creativity, expressed through his artistic imagination, was brought to life in the robot character.

Beings of otherness were experienced through the children's imagination and connection with the qualities of animals and their drawings. These narratives of creativity reflected the issues in their lives; needing to protect themselves, needing strength and courage, adaptability and resourcefulness in meeting life's demands. They were narratives of desires for the self that could be imagined within the self. The power of metaphor enabled a different reality to be imagined, in which the self could be transformed (Lakoff & Johnson, 1980).

Part of the story. Myths, fairy tales and fables all present the struggles endured on the quest towards the self's development. Their purpose is "to carry the spirit forward" (Campbell, 1949, p. 11). Bettelheim (1975) believed these stories enabled children to remain connected to their inner world, as well as providing possible solutions to and ways of understanding life's conflicts. The journey of the hero is a common theme (Campbell), connecting with children's aspirations to aspire to 'something more', to feel connected with 'something other'. Connection to the stories of other lives,

whether real or imagined, helps children to understand and live out their own with perhaps more clarity of the self's struggles. The characters the children spoke of vibrated with resilience; to ongoing struggles, danger and in the desire for expression of the self.

Movies, videos, novels and computer games created spaces of expression where children could live out their desires for agency and courage. Rambo experienced a sense of agency coupled with power through not only his responses to bullies (see Chapter 7, When people are mean), but also the movies he liked to watch like *Gladiator* (Franzoni & Scott, 2000), "Yeah that was mad. He chops his head off. *Oh, that was a violent film wasn't it. I wouldn't have liked to live back then. I would.*" Like some of the other children he was able to vicariously live and experience feelings of agency and active resistance through movies or TV shows. Michael Jackson's choice of reading was surrounded by movies, "Yeah I read Spider-Man books but I've finished them. Cause I've got three of them and I've finished all three, based on the movie. I've seen that movie." *Spider-Man* (Koepp & Raimi, 2002) was Michael Jackson's favourite movie, a character and tale of alterity, bravery and physical mastery.

Cerberus had a passion for, and vast knowledge of Greek myths. He indulged his passion through videos. Heroes were engaged in quests of self-expression through challenging themselves. Through these videos, like Rambo and Michael Jackson, he was able to experience a life of danger and courage, a hero's journey (Campbell, 1949) of living the life he chose, confronting and besting his foes.

His love of learning about mythical and ancient beings stemmed from his curiosity, "I just, I just, like . . . well, I never knew, I only know, known about . . . the

three headed dog [Cerberus] I think, the three headed dog and the lion [Nemean lion], Hercules and like that. See I know a lot about Hercules, and then . . . I'm looking in my big book, like we got a encyclopaedia . . . and them say, like them have them myth animal, like the half man half bull [Minotaur], and I wondering what that was, like . . . and like I start from that and then I get to know about the lady with the snake head [Medusa], the three sisters with the snake [Graiiai]." The Greek mythical heroes Hercules, Theseus and Perseus (Graves, 1961) used their intelligence and strength to conquer nightmarish foes and outwit their challengers in order to gain the prize or treasure. As Cerberus did not consider himself to be brave, myths seemed to enable him to experience danger and difficult emotions vicariously (Engel, 1995). He could transcend his own fears and physical limitations through the deeds of others.

Max, Deatherford, Elvis, Elliot and Ian Welsh also spoke of vicarious experiences or the desire to experience alterity through reading. These were often stories of hero quests, courage being lived in the everyday of parallel worlds of being. One of Max's three wishes was "Every book from the series called 'His Dark Materials'". This trilogy by Philip Pullman, chronicles the adventures of a girl called Lyra as she battles with and outwits unscrupulous adults and magical demons, despite or because of her youth, thereby bringing justice to the vulnerable.

In the first of Pullman's books, *Northern Lights* (1995), which Max was reading, Lyra stops an adult plan separating children from their 'daemons' (their spirit). Lyra's courage and determination on her quest speaks of sustained resilience in spite of overwhelming odds. In these experiments of separation children and their 'daemons' die. These strong narrative metaphors speak of the intertwining of body and spirit,

neither being able to live (be in the world) without connection to the other.

Reading for Deatherford added further meaning to his life, "Yeah I like it, cause cause I've got heaps of books in my room." He particularly liked books by the author Jackie French, who writes stories of children befriending alterity or defeating threats in their everyday life. Elvis especially enjoyed reading Paul Jennings' stories and *The Adventures of Captain Underpants* (Pilkey, 1997). He named *Captain Underpants* as a hero, though he laughed when he said this, describing the character as someone who was funny, happy and fast, but also fat and afraid. Importantly, this was a character capable of achieving despite being afraid, which appeared to relate closely to Elvis' (desired) perception of his emotional identity. Like Max; Ian Welsh, Elliot and Elvis spoke of their enjoyment of computer games where skill and bravery were needed to survive and win. These games enabled yet another reality of being and experience of agency, where faith in the self was essential.

Becker (1992, p. 68) argued, "In reading, meaning is made as the child becomes part of a story and the story seeps into his or her life." The children's identification with the heroes of stories, whether through text or image, spoke of a taking up of the qualities and values of these characters (Ricoeur, 1992). Spiritual qualities of courage, faith (in the self) and hope contributed to a resilience to continue to engage in life's struggles while never surrendering the self. Meaning was made as each child became part of an alternative narrative of being, one that could also enter their life. The power of these narratives offered understanding and hope, and an alterity of being that could transcend the daily negotiations of life (Bettleheim, 1975). Tales of transcendence enabled a reshaping and reinterpreting of the self in relation to the world.

When I Grow Up

The children's narratives about their future occupations, what they wanted to become, often reflected their current desires for agency, connection and creative expression. The strength of their desires lies in the meaning these occupations held within the expression of their identities. There was an intertwining of the present self with the future self through the purpose these wishes, hopes and dreams gave to their present lives.

Brett, Rambo and Elvis expressed desires for wealth and agency. When I asked Brett for his three wishes, his reply was very direct, "The first wish would probably be, to, okay, be the, richest man in the world. The second would be, to be the, most known person in the world. The third one would be, to be the, smartest, in the world." His wishes were for power, agency and recognition. Brett's desire for wealth echoed Rambo's wish, ". . . to be rich." When he grew up Brett wanted to go to university and study law, which gave purpose to his learning at school (see Chapter 7, Narratives of Learning), "I just picked that particular thing, and, then went from there. It's just how, well the money, and just. Yeah. I'm not sure. Or if I don't want to do that, I just want to be a politician or something. . . . that's just the choice I'd just like to do that just to be, it would be a good experience, going round the world, because you get your stuff for free." He expressed very practical desires for money, travel and freedom, of leading a life of agency. His career choices are interesting if viewed from the perspective of voice, justice and helping others. However, this perspective did not seem to be within the thoughts he shared with me when talking about these future occupations. Rather, they were woven into the thoughts he expressed about his present life and his concern for

others.

Elvis' three wishes also related a desire to be seen and valued, to be known. He wanted to be "famous", to "... be the richest person in the world", and to go "... anywhere in the world." These wishes also speak of his desire to have power (agency) and access to a world where there were no (physical) limits. Adults, or those older than he, were seen to have the agency he desired, "I could do what [Brother] wants to do. I could do basically anything." He would have the ability to experience other worlds and realities, again with an absence of physical limits, a transcendence of his current self. His child status conferred feelings of limited agency, which seem to merge with his feelings of limited agency through his experience of disability.

Cerberus, Lisa and Bobby all shared a love of and strong connection with animals. In our initial meeting Cerberus told me he wanted to be a vet. Although he didn't place this desire within either his hopes or his wishes and never spoke of it again, I wondered whether it was part of his wish to perform magic with animals but would be more seriously considered a hope. Perhaps it didn't 'fit' with his hopes based on religious faith and was therefore not included in his hope drawing. In our second conversation Lisa had talked about wanting to be a vet, and she raised this again when talking about daydreams. "Yeah, I'd like to be a vet when I'm grown up. I think about me helping animals." Her love of animals entwined with her life's purpose. Bobby was also interested in being a vet. For him, animals were often preferable friends and company to humans.

Many of the children's future desires embodied being seen by the world. Elvis also wanted to be an actor and a model. He enjoyed looking at the pictures of famous

people in *TV Week* magazine, which spoke of his interest in the appearance of fame and how he may have perceived what was physically desirable to others. Both of these occupations spoke of a wish for public acknowledgement and acceptance, of becoming other than the self, creating an alterity seen and valued by others. His desires speak of a wish for 'witnessed significance' (Fleischman, 1994), the creation of identity through the acknowledgement of society.

As Groovy Princess and I were talking about what she liked to do she told me, "Yeah, I like dancing and singing. I'd like to either be an actor or a dance[r], singer or a hairdresser." If she was able to be all of these at once, "Then probably everyone would want to come to my hairdressers." When I asked Groovy Princess in a later conversation if we could talk about wishes, she replied, "Yeah, I've got quite a few. I don't know. Like I'd wish to be a grow up, to grow up to be a hairdresser, or a singer and dancer. Or even a Paralympics . . . Swimming." Her future desires and joy in the present held strongly in her thoughts.

Chontelle shared Groovy Princess's desire to be an actor or a singer. Chontelle's wishes reflected her delight in, and desires for, agency, transformation and creative expression. She also wanted to be a fairy, "Like Tinkerbell." Someone who could make good things happen. She was very definite about what sort of fairy she didn't want to be, ". . . but I don't like to be a tooth fairy though, then be stuck picking up people's teeth." For her this was a very practical consideration for a future fairy. Chontelle's wishes to become a singer performing on stage were lived through her dreams, "I dream about that . . . sometimes I dream about like somebody, I'm on stage and I didn't know that my mum was watching me on stage sometimes." She sang in bed sometimes and

daydreamed about being a singer, creating a future self within her present self.

Elliot wanted to be, "When I grow up, probably a singer. Or a swimmer." Ian Welsh wished to be, "A professional swimmer, swimmer and basketballer." These choices reflected his passion for sport, for physically excelling, and the sense of skill and achievement that motivated him, "Swimming's probably number one for me, cos I've, if I've got this far . . ." Bobby was interested to know whether he could be a soccer player if he wore glasses. Brett also had other aspirations, "Well I did want to be a . . . pro soccer player or football player, but well, soccer player is still there, but football player I think is just, I just don't think I'd ever be able to. So, I've just, forgotten all about that, and I do want to be a soccer player. I probably will try, but, I don't know if I'll succeed." His desire to play professional football was quashed by the impact of his need to wear his glasses to see (see Chapter 8, Part of the team). For these boys their desires for future sporting excellence were bound up with their current passions for sport.

Being an author was Cheezel's wish for the future, "I want to be an author. Because I love reading, I love reading." For Cheezel, reading was his favourite pastime, "I read all the time. I seem that I can't even live without reading." Reading was breath, life. He considered it to be important enough to him to take a photo with the camera I had given him, "I just took a picture of all my, books from my favourite authors." Although many of the children enjoyed reading, for Cheezel it was a central passion, one enfolded with his creativity of imagination and expression.

Rambo expressed other desires, "I'm going to go in the Army? With my friend." He would be, "Do you know those people that go underground and they clean out

mines? And then they take a step from it, KAPOOM. They're going to pieces . . . it's called a mine layer. And my friend's going to be a helicopter pilot." His passion for physical activity and challenging himself was reflected in his choice of a career of danger and excitement. He would also remove danger from the path of others, something he did in caring for his sister (see Chapter 6, Sibling relations), defending his brother at school (see Chapter 7, When people are mean), and had done in the past with his mother (see Chapter 6, Acts of courage).

Barney had chosen a quieter occupation, wanting to be, "A office lady." She told me office ladies, "Do some work. . . . And I'm getting a really, things like a table and papers and stuff. And that's all." Her mother operated a business from home. Barney's future desire appeared to identify with and speak of a desire to experience the purpose and agency she saw in her mother's life.

Except for Groovy Princess's desire to be a Paralympic swimmer, the children did not mention role models of adults with disabilities enacting the occupations they desired. This had not restricted them in their choices, which spoke of them seeing themselves as 'complete' children who would become 'complete' adults. Their desires for their future selves were the same as those of children without disabilities (Shah, Arnold & Travers, 2004); they had not internalised the limited expectations of others. This contrasts with the research of Howard (1996) where children with disabilities had either not considered a future occupation or had restricted expectations of their future roles. For the children in this study, their "occupational dreams" (Egan & Townsend, 2005, p. 201) challenged cultural scripts of limitation and invisibility.

Implications for Practice

The interplay between categorical and individual identities . . . contextualise[s] the experiences of childhood which children have, and their re-telling.
(James, 1993, p.28)

If, as occupational therapists, we wish to enable children in the ongoing creation of their identities, we need to understand how children perceive their identities; as human *beings*, as children, and as children with disabilities. The children's narratives of self spoke of a resilience of individual identity above categorical (James, 1993) or social identities as children with disabilities (Hockey & James, 2003). They could not be read simply as a 'disabled body', a social inscription on the body's surface (Grosz, 1994). Their narratives ask others to see them as a lived body, one of complex interiority and intentionality (Merleau-Ponty, 1962). The children's bodies did not define who they were. However, their difference influenced their identities because of the perceptions of others and the limitations it placed on their engagement with the world. Their bodies were part of who they were within the world. Their qualities, emotions, interests, hopes and dreams were more important in their definitions of self.

The embodiment of spiritual qualities expressed in the children's narratives speaks of an engagement of the spirit with the self. Drawing upon the self's spiritual qualities and drawing them into the self through their experiences created an intertwining of spirit with self and others (Moore, 1996). As posited in Chapter 2, there was a lived relation of the spirit with the world, through the self. Identity was created and recreated through each story (Christiansen, 1999).

The uniqueness of the children's self narratives asks us to consider how these may influence children's ways of being in the world and how they may choose to

respond to our approaches. Children's understandings of themselves are not usually foregrounded within client-centred practice. Knowledge of children's selves comes from others, or is learnt incidentally through children's responses. If we wish to build effective relationships with children, based on trust and respect, then we need to ask children to tell us about themselves (Mattingly, 1998). Their stories of identity will enable us to hear what holds purpose and joy in their lives. We will discover how they see themselves in relation to the world and the dreams they have for themselves.

These understandings will in turn enable us to engage with children in ways that have meaning for them, through stories, animals, movies, or computer games. Entering the world of metaphor (Fazio, 1991; Lakoff & Johnson, 1980) can bring insights into what children see in and desire for themselves. Through this avenue of understanding and connection, children can tell us of the spiritual qualities they seek to embody within their daily lives. Within their experiences of courage, otherness, and wishes for the self, the children in this study were reflective narrators of their identities. They expressed their wisdom as they sought to express their identities within their experience of being in the world.

As occupational therapists we need to remain conscious of enfolding children's present and future occupations within current skill development. Skill development should consider more than the present and functional future of self-care, mobility and developmental task engagement. Our intervention practices need to incorporate the ways of being children express and to respect the power of the purpose of becoming within each child's being. We need to seek an engagement with children's hopes and their faith in themselves. As they imagine themselves, we need to approach children as having the

potential to be more than we have imagined (Moustakas, 1959). Moving beyond limitations of the current 'occupational imagination' will enable us to more clearly understand what children experience and understand of their identities.

SMILE ! YOUR HAVING A GREAT DAY

Chapter 6: The Meanings of Home

'Family' can be seen not just as a site which bestows identity, but also a vehicle through which individuals seek to *create* identity.
(Hockey & James, 2003, p.158)

Within occupational therapy, the shift to family-centred practice (Hanna & Rodger, 2002; Humphry & Case-Smith, 2001; Mulligan, 2003) positions the 'family' in a more enabling space (Dunst, Trivette & Deal, 1994). When occupational therapists structure intervention in this space, family voices should be heard and their desires respected. Even so, in this model of practice, children with disabilities may be centred but they largely remain observed and silent. Parents are positioned as 'the experts' on their children. Occupational therapists facilitate children to develop their roles within social and cultural scripts (Lawlor, 2003b). However, children are not yet enabled to tell their own story of being within the family. Although the model speaks of respecting parent/child and sibling/child relationships (Humphry & Case-Smith) the authority remains firmly with the parent.

The ways in which children seek to create their identities through family relationships are influenced by societal constructions (Hockey & James, 2003; James et al., 1998). The impact of children with disabilities on their families, though acknowledged within research as potentially positive, remains focused on the demands children's impairments place on others. Children with disabilities thus remain positioned within a model that considers them through a gaze of 'burden and lack' (Davis & Watson, 2002; James et al., 1998). This creates tension for therapists wanting to enable children to create identities of agency and capability.

As occupational therapists we have limited knowledge of the reciprocity within family relationships, so there is limited knowledge of home as a place of emotional meaning (Hasselkus, 2002; Howell, 1983; Humphry & Case-Smith, 2001; Rowles, 1978). Professional knowledge has privileged 'doing' over being (Moore, 1996; Rowles, 1991). This is evidenced in the focus on objects, tasks and activities rather than the relationship between children, tasks and context. Assumptions about 'meaning' and children's knowledge require further exploration. Exploring how individual meanings are enacted within the home enables different perceptions of home as a place in which children's identities are created.

These different perceptions are relational enactments of self, where children enfold themselves and are enfolded by the emotional relations of place (Moore, 1996; Rowles, 1991). Home is an integral part of "composing a life" (Bateson, 1996, p.7). My research seeks to create a further shift in practice knowledge, to one where children with disabilities actively experience and contribute to their home world, creating and expressing their identities within its boundaries. This chapter analyses and explores this aspect of children's lifeworlds in relation to occupational therapy practice, and how children draw upon spiritual qualities to negotiate their identities through reciprocal relations.

Family Bonds

My shield. For all of the children family relationships provided experiences of love and belonging. These experiences contributed to their resilience when interacting with the world outside the home. Elliot spoke with wisdom about the foundational

security of belonging, being cared for and loved by his parents, and the importance of this relationship in other contexts (Bettelheim, 1987).

When I asked him what helped him to feel good about himself he replied, "Well being near my family, with my family, out of like harm's way, away from the bullies, away from the people that hurt me. Just, just safe, in my house, where nothing can harm me. So like my family and my house is like my shield. It shields me against those things. And so's my dad's car. But as soon as I get out of my dad's car, which is as soon as I say goodbye to my dad, my shield is gone and I'm in the company of like my teachers who I've just met and like all of this so my shield is gone. But I still have a shield with me. My heart and what my thoughts inside me and good thoughts are my shield around at school. So that's my shield. But the biggest shield of them all is when I'm with my family, that keeps me safe, that would be mum and dad." He knew he could care for himself through the strength of his heart and thoughts, but he also knew that his parents and being at home gave him the greatest feeling of safety through their love and care.

Elliot spoke of home as a shield, a place of security built through the protection of family ties, "a literal and symbolic circle against all external threat" (Berkeley, 1985, p. 36). His shield extended to the outside world through his father, protecting him and making him less vulnerable to hurtful experiences. The power of the protection of this relationship gave Elliot the emotional strength to meet the challenges of his everyday world of school (see Chapter 7) and to continue to express his identity within the uncertainty of school relations (Bronfenbrenner & Morris, 1998). The external protection of family became internalised, which added to his resilience. He was



Drawing 4: Ian Welsh's 'My Family'

supported by these primary connections (Hunter, 2001) of love and belonging where his impairment was not foregrounded in his relations with others. Elliot's metaphor of a shield highlights how spiritual qualities can be a source of resilience to counter the disabling relations beyond home.

Parental relations. I did not ask the children directly about their relationship with their parents. Rather their narratives emerged when we were doing the feelings and qualities maps. Stories also emerged through being in the children's homes and in the flow of our conversations, highlighting the importance of being with children in a safe and enabling space in which they could express themselves. Parental and extended family relationships informed the children's beliefs and values about themselves and the world in which they lived (Antle, 2004; Bronfenbrenner, 1979). Children had unique relationships with their parents though there were commonalities across these relationships. The commonalities included seeking and giving love and respect, caring for each other, participating in shared meaning through storytelling and activities, and negotiating boundaries and expressions of the self.

As parents moved into and out of the space of our meeting, the children offered and received connections of love, belonging and trust with their parents. Barney considered her drawings in our second conversation deciding, "We'll keep it for daddy. . . I'll keep that. . . . And that for mummy." She gifted her artistic creativity as an expression of her love. During our first conversation, Ian Welsh often called out to his mother to tell her what he was doing, showing her his drawing, "I'll show mum. Mum, mum, there's the family." He shared his sense of belonging within the family and connected with her through his artistic expression (Drawing 4). Like Ian Welsh, Cheezel

wanted to connect with his mother through his creativity, "Mummy, look I made a flower and a spider. I want to show her. Mummy, look I made a spider and a flower." In our second conversation, when Lisa had finished her drawing of *Star*, the horse from one of her favourite novels (see Chapter 5, courage), she insisted, "Have to show mum. Mum, do you like this it's Star? *Oh [Lisa], it's beautiful! There's something missing though. The mane. That is a beautiful picture, you're getting better and better at drawing. Yeah.*" This brief dialogue gave Lisa praise, direction and encouragement, which her mother employed during all their exchanges over her artwork. In these interactions Lisa's self and creativity were affirmed and her sense of identity as a capable child was valued.

These children actively connected with their parents. They built on their relationships of love through offering expressions of themselves, seeking to share themselves and what was meaningful at that moment. The warmth with which these expressions were received reinforced to the children the value of their individual expression, and the parents' perception of the importance of the children's love for them. These interactions reaffirmed the foundational security of the relationship as one in which the children could develop a strong sense of self (Rogers, 1951).

Chontelle and Cerberus expressed their selfhood through the agency of their voice within their relationships with their mothers. Chontelle had a warm and relaxed relationship with her mother. Her mother joined our conversations and participated in our activities. While we were drawing, Chontelle often teased her mother, "Ooh, you're going to be crazy . . ." complimented and reassured her, "You're a good drawer"! She asked for help with her spelling, "Is that how you spell people"? She helped her mother

with her drawing, "Mum I show you a teapot, you've got to make a hole here" and was directive, "Don't draw me ugly." She also wanted to know how her mother felt, asking her, "... you feel sad when I'm in hospital"? Chontelle was interested in her mother's responses and feelings, wanting to understand, to deepen their connection.

She became anxious whenever her mother left the room, "Mummy, hurry up"! Her mother's presence gave her 'voice', through her mother's understanding, their strong relationship, and her mother's ability to interpret for her. From the beginning of our conversations, Cerberus was vocal and directive in his interactions with his mother, as his mother was with him. They argued with and talked over each other, seeming very comfortable about doing so. When his mother showed me his book of drawings, he said, "Mum! Start from the beginning, you starting from the end." Like Chontelle he had a 'voice' in his relationship with his mother. Their interactions demonstrated the 'intersubjective' nature of children's identity formation as an ongoing relationship.

Both children demonstrated their courage to be themselves (Tillich, 1952) expressed through voice, within the relationships they had with their mothers and the relationship they then established with me. Within the dialogues of these children with their mothers, the children's voice was as strongly present as the parents'. Relationships were reformed from traditional roles of parents as authority figures to that of partners in creating moments of belonging. These moments contributed to the children's positive sense of identity. The mothers' participation in the way their children chose to relate enabled these children to speak out for themselves within the emotional safety of the relationship, to be unafraid of expressing their opinions. Their opinions were valued and heard (Moustakas, 1959; Rogers, 1951).

Compassion was evident within the relationships children had with their parents and was often expressed when we were doing sad maps. Bobby's mother had hurt her eye. He asked me to put this on his sad map, "She went there, it was like a little stick. It was sad cause it was real sharp and my mum smashed and her eye got blood. All blood down and all cut." He spoke with concern in his eyes and his voice. There had been times in Brett's life when he felt sad, "I found out that my uncle had died at the age of two. Dad's brother. Got hit by a car. Got hit by a ute, truck. And dad saw the whole thing. That was sad." This story expressed his empathy for his father's trauma and loss. Loss of his great grandmother was another sad time, "When she died, that was sad" and when bad things happened to people he loved, "When just, something bad happens or, happens to my mother" like people dying or being sick. Cerberus considered the loss of someone important to him as a time of sadness, "Taking away things. Like take away mum or, someone." Cerberus told me stories of the difficult relationships within his father's family, as he seriously highlighted for me the troubled time his father had experienced as a boy, "... dad used to have a horrid life." He also spoke of how these extended family relations continued to affect their lives.

Narratives of hope and faith within family relationships emerged when we discussed spiritual qualities. For Brett, hope and faith were entwined, "Hope means to, believe. That you've got to believe, I think you've got to believe that you, that there is hope and it can happen. *So is it a bit like what you said about having faith?* Yeah. I think it's practically the same thing. You've got to do the same thing." When I asked him whether there had been a time where he'd had to have faith or hope, he told me, "When, I have to have hope now, for my nan's mother's sister, the one that died's sister.

She's in the hospital. She's 91 and she's, she can't walk. So, yeah. I hope there. . . . But nan's hoping when she gets better, that she can take her out into the grounds and walk her around." Brett wove his hope with his grandmother's, expressing his compassion for both women.

These children were very aware of the emotional and physical pain in the lives of those they loved. The children's experiences of impairment and disability contributed to their empathy of their parents' experiences. They expressed their caring, concern and empathy through the sadness they felt on behalf of others. The difficulties faced by these important adults in their lives evoked the spiritual quality of compassion within the children. For these and other children in the study understandings of love, compassion and hope were shaped through their involvement in and knowledge of their parent's lives.

For all the children in this study, identity was constructed through the giving and receiving of love and a sense of belonging within family relations. Their narratives of parents, grandparents, aunts and uncles spoke of enfolding identity within these significant relationships. The children were actively co-creating the relationships through their desires of and responses to the other. Being a child within a family is not only to receive, it is not simply that parents or other adults emotionally act on or give to children, children also act on and give to parents (Bronfenbrenner, 1979; Dillon, 2002; Hallden, 1994).

Sibling relations. Like the parent narratives, narratives of siblings emerged while we were doing feelings and qualities maps. Narratives also arose through being in the children's homes, where siblings were often present and became part of the

conversations on family life. Within the narratives the children shared, there was no mention of enacting the role of being a sibling with an impairment. Rather their narratives focused on the everyday interactions of being a younger or older brother or sister.

Cheezel and Rambo openly expressed love towards their youngest siblings. As older brothers, they demonstrated their capacity to accommodate their younger siblings' needs. Cheezel's youngest brother was a baby and he was very affectionate and caring towards him. Cheezel's creativity reached out to his baby brother, "Yeah, you can hear him crying a lot. Yeah, usually it's quite annoying in the car. Yeah but, sometimes when I'm, usually when I'm with him, he's usually not crying, I mean, I like to have thousands of ideas of like I know thousands of ways how to stop him from crying. . . . Well I just experimented on them." He persisted with the challenge of soothing his brother until he succeeded (Bandura, 1986). His creativity was expressed through resourcefulness and care (Sheldrake, 1989).

Rambo's little sister would often want to join in while he and I were together. He was patient and accommodating while seeking to maintain his own space, "Here you are, take these with you. And make a little toy thing. Say 'Mum you make me a twirly thing'. *No*. Yes." He then decided to renegotiate rather than argue, "You can sit next to me okay." Rambo and his little sister fought, "Yeah [Sister] plays with me. I just muck around and you know she flies and hits me. *And then it's on?* Yeah, mad." He didn't get angry with her when they fought or when she went into his room, "No, she can touch everything." Rambo's creativity was embodied in his adaptability and flexibility (Sheldrake, 1989) in meeting his little sister's demands.

Through these relationships the boys were expressing their love and care for another, and receiving love in return. They knew themselves as efficacious within these relationships, as they responded to the needs of the other in constructive ways (Bandura, 1986; Bruner, 1987). Their relationships with their youngest siblings were sources of joy, through play, laughter and emotional warmth. They were the child with an impairment within this relationship but they were not the dependent one, rather the one to be depended on, affirming their belief in themselves as agentic within these relationships (Maslow, 1999; Rogers, 1951).

The everyday of negotiating space, time, attention and the expression of identity was narrated through stories of sibling relationships. These relationships were often close, though disagreements occurred (see Negotiating conflict, below) and siblings' names were often placed on children's angry maps. The children expressed love and compassion towards their younger and older siblings. They tolerated the paradox of knowing their siblings were important to them but also challenged them in ways they did not like.

Barney and her younger sister had a close relationship. They played together, as her sister explained, "We play like babies and that. Mums and babies, and she's normally the baby." Even though she was older, Barney assumed the dependent role in this game with her more physically able sister. Although it was a reversal of traditional roles, it was acceptable within the rules of their game. Barney also liked to be by herself, listening to music, to which she added, "And sometimes [Sister] annoys me" disrupting the pleasure she experienced in being alone and immersed in the music.

Barney, Groovy Princess, Keeta and Nina became annoyed at the intrusion of

their siblings when they wanted to be by themselves. For these four girls, all eldest siblings, their younger siblings placed demands on their time, privacy and attention, which they sometimes resented and at other times accommodated. Experiences of connection and separation were constantly renegotiated, with the girls' understandings of the role of older sister being reshaped with each experience.

Lisa spoke about qualities desired in another, "... sharing, sometimes, if they want to." For Lisa it was also important for others to be "nice" and to give compliments, qualities that she saw in her mother but found difficult to see in her siblings, "... but about my sister and my brother being nice is a tricky question. Oh they're, they're just annoying and my brother's not nice. He ... he teases me in a mean manner, annoying manner, a noisy manner when we're playing. And some, and he used to sneak into my bedroom and read my books." Her older brother transgressed her play and privacy. Her perception was that he did not respect her.

She admitted that her big brother's behaviour made her angry, "When [Brother] teases me. . . . [Brother] annoying me. . . . Sometimes [Sister] is annoying. Well she's immature. Sometimes when she's being silly. . . . But we play with each other. We, I, mean that sometimes all three of us play with each other. But [Brother] doesn't really want to play." She saw her brother as someone who got cranky and yelled, and "Sometimes I argue back" asserting her agency through resistance. "We're not really friends, we, we sometimes hate each other. Sometimes we be silly together. . . . I like being silly." Their relationship was one of ambiguity and difficulty in which she held a wish that he would share and enjoy the moments of play and having fun.

Nina got into trouble with her parents, mainly due to the fights she had with her

younger brother who annoyed her and made her angry, "Fights over the controls [for the PlayStation]. . . . I was using the see through one and he wanted it. And he started screaming at me, so. . . . Before he annoyed me more than now. Because when I went to my room and he wanted to play with me he kicks the door. But now he doesn't do it. Because he's older. It was a long time ago." Through her wisdom she was able to forgive him for his younger, more immature behaviour towards her.

She was prepared to be understanding and could empathise with her brother's predicament of not having a friend to play with, "But there's a, there's some Kindy students in our school that live in this street. But he doesn't know them well. He doesn't know them well so he doesn't [invite them over to play]. And he doesn't have friends at school." She was conscious of her little brother's needs, acknowledging his desire to be included in her play but sought to play within her own space. This was a reflectiveness and responsiveness of self she shared with Keeta and Groovy Princess.

Sibling relationships are usually reported from the perspective of the siblings of children with disabilities (Banks et al., 2001; Fleitas, 2000). Research has explored the stresses and demands placed on siblings and the effects of the relationship on their identities. However, it has not explored the perspective of children with disabilities and the ways in which they negotiate and contribute to their sibling relationships.

All the children in the study engaged actively in shaping the relationships they had with their siblings. Through these relationships they offered and evoked love, belonging, trust, joy, and compassion. The shadow sides of anger, separation, distrust and sadness also emerged. They sought to understand and forgive their siblings and to sustain their belief in themselves, maintaining a resilience of self through these

connections. These negotiations with and reshaping of the other and the self contributed to a foundational understanding of the self in relationships with children outside of the family (Minuchin, 1974; Neven, 1996). They created an understanding of the value of the self as experienced by other children, how the self was accepted and challenged. Their relationships with siblings helped them to identify the qualities needed to be drawn upon when relating to others in order to meet the needs of the self.

Their identities were fluid in these roles, responding to the dynamics of these relationships as Hockey and James (2003) noted for children without disabilities. None of these children spoke of the influence their impairment may have had on their interactions with their siblings. Their understandings and ways of relating to their siblings reflected their perception of their role as an 'equal' child within the family. This equality was in stark contrast to the interactions children experienced outside the family (see Chapter 7).

Pets as family. In the life of the children, the role pets appeared to fulfil was that of a friend. Pets were friends who would always love them, and to whom they could express their love and share moments of joy. Children also spoke of pets that had died or been sold, their sense of loss still evident long after the separation. As many of the children had limited friendships, their pets were a very real and powerful source of belonging (Serpell, 1996). Pets enabled the children to relate to another without expectations of a disabled identity.

A number of the children spoke of the importance of their pets. Pets were considered an integral part of the family. As family members were placed on the children's happy maps, so were their pets. Bobby voiced a strong connection with

animals, especially dogs. In our first conversation, where we began making things with play doh and pipe cleaners, he was keen to know, "Any dogs, can you make dogs"? Later in this conversation I asked him, "*What's something you'd really, really like to know how to do*"? His reply expressed not only his desire to be creative but also his love of dogs, "Make something. . . . Like dogs, make dogs. *You mean with this stuff* [the art materials] *or?* Yeah. *Yeah? Or scientific experiments?* Both of them. *You want to make dogs?* With both of them"! He wanted to keep all the dogs he made at home, creating a group of friends to substitute for the difficulties he experienced in the relations with his siblings (Brodie & Biley, 1999).

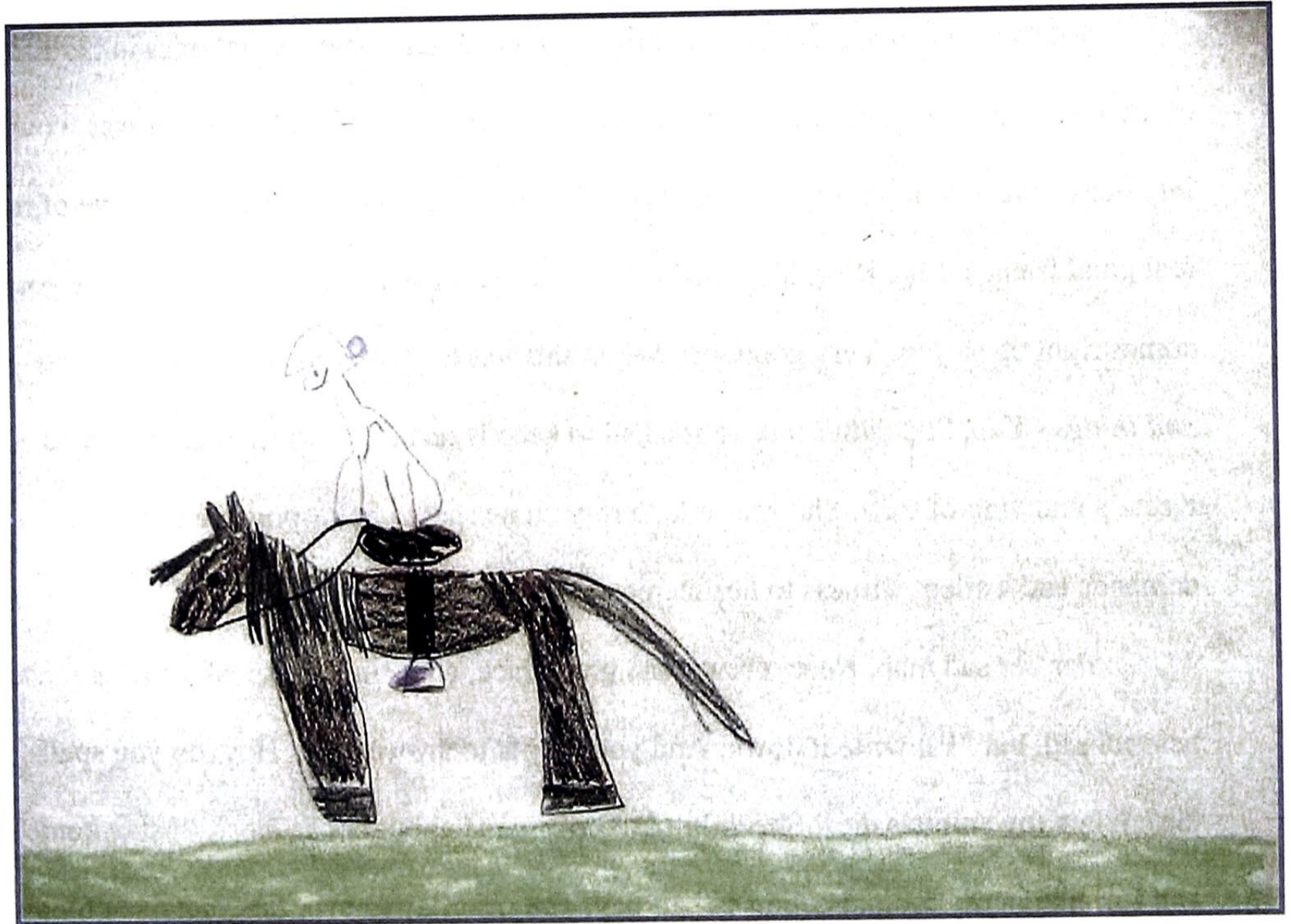
Elliot's family had a dog and goldfish, but he wished for a pet of his own, "And I just want like, I just wish like I could have my own pet some day, like a bird I could have, probably when I'm 11 or probably this year for Christmas, I might want a bird for Christmas." He wanted a bird, "Because like I just want some company in my room. Just like to, when the bird chirps or whatever he will do when I get him for Christmas, I hope, he will just keep me company and I'll feel relaxed." Although Elliot had a brother and sister, his brother was at boarding school and his sister lived with his mother so he spent much time at home without the friendship of his siblings. The company of a bird would help him feel a little less lonely.

Cerberus drew the head of a rabbit he had once owned on his happy map, "Know him [referring me to his drawing]? I used to have a rabbit . . . called Peter. . . . I had two rabbits, one called Sansun, Samson, and one called Peter. I used to like Peter most cause I haved him from a little baby." Although Peter was no longer in his life he was still significant within Cerberus' memories and his understandings of love and joy in

relation to another. Cerberus had grown up surrounded by animals and family stories of animals, some of which he shared with me. They were stories of hilarity and danger, and had meaning for him in terms of connection and identification with his extended family, his parents' past, and his love of animals.

Keeta also had a great love of animals and had had some special ones in her life, especially a cockatiel who was her friend and visited her in hospital. Her pet was woven into our conversation on trust, "Yeah. I used to trust her. Cause she used to be one of my real good friends. Like if I said come back here or else I'll smack your bottom, she goes, comes right up to you. Very good girl. When she was here. *So did you tell her secrets and things?* Yep. She didn't talk so she had to keep it secret." This friendship shaped Keeta's knowing of trust. She was able to rely on her pet to be responsive to her demands and a silent witness to her secrets (Serpell, 1996).

For her sad map, Keeta drew a sad green face, choosing not speak of what made her feel sad, but "I'll write it down. And you've got to answer. . . . How do you spell die? When my animals die." She didn't talk to anyone about her sadness, "I stay home and I'm like in my room. Feeling sad all day. The next day I never talk, not even for a question or do news [at school]. I say I forgot. When I had it in my bag. They [her parents] just say, 'We won't get another one but you can probably get a guinea pig'. And I said, 'I don't want a guinea pig I want a bird like [Pet]'. But I've had too many birds that have died from the same thing." Despite their deaths, she still yearned for another. When she was in the privacy of her room she expressed her feelings through drawing, "I stay in my room all day drawing a picture that looks really real instead of like pretend on the fridge [a drawing she had done the previous week]. Like I draw it



Drawing 5: Lisa's 'Jasmine and I'

with the shading on the eyes." Keeta felt a deep sense of loss of these special friendships, which she conveyed through the detail of her drawings, expressing the sadness she kept hidden from others.

For Lisa, horses were her greatest love, "On a horse, that's my favourite place." Lisa's first drawing was of a horse she had when she was younger (Drawing 5). She initially drew her horse standing in a green field, leaning forward with a sense of imminent movement, and then chose to include herself riding her. She placed herself as an outline, not quite real, perhaps connected with her knowing that this was something she could only do in her imagination. She still missed her horse, "I was six when I got her . . . about seven we moved out [from the farm], seven and a half. *So what happened to [Horse]? Oh, she sadly got sold.*"

These narratives of the friendships of loved pets speak of the children's desire for relationships of trust and joy enfolded within an unconditional acceptance of the self. Within these relationships, children expressed their love through caring for their pet, experiencing the sadness and loneliness of loss when a pet died or was sold. Desires for a pet of their own choosing spoke of the need to choose another that met their needs for belonging through companionship and play (Serpell, 1996). A pet perhaps met their desire for an otherness of self, as they had spoken of in their narratives on being an animal (see Chapter 5, *Imagining the self*). The emotional value these and other children placed on their bonds with a significant pet highlights the importance with which these relationships were considered. They were family.

Boundaries of Self

For the children, the dynamics of family relationships evoked the need to

negotiate the boundaries between self and other. The rules of engagement were experienced differently between parents and children, and between siblings. The children's understandings of these rules and the need to operate within them sometimes caused anger, frustration and sadness. The children's resilience was called upon when they needed to deal with difficult issues and to make sense of them (Bruner, 1987).

Rules of engagement. The experience of love and belonging between parents and children was sometimes conditional. During our second conversation, Cheezel's father briefly came into the room and Cheezel responded by using his creativity to connect, "Look how smart I am. What does this look like? What do you think this is? Daddy, what do you think this is"? He sought praise and recognition for his expression of self, relating to his father in a very different way to his mother (see Parental relations, above). He needed to be seen and valued rather than simply offering his presence through his creativity. Max thought that adults, "I think they mostly get bored [with kids]. Yeah, I think so, when the kids want to play something, and they want their dad to do it, yeah, I think the little kids do this." He believed this didn't happen so much with older kids, "No, bigger kids do lots, by themselves, usually grown up enough, go play with a friend, that's what I think. . . . In the holidays I do hang around with my friends a lot." As children got older, Max believed friends replaced the need for parental connection because, in his case, it was not freely given. His belief was a reflection of his experience.

For these two boys, relations with their fathers seemed to depend on the boys acting as the other wished, rather than receiving love simply through being themselves. Expressions of self were sublimated to meet the desires of the other and the roles they

were expected to play (Bronfenbrenner & Morris, 1998; Minuchin, 1974). These two boys perceived that their relationship with their fathers was based on particular rules of engagement where the opinions and desires of the father were paramount. They altered their way of being, Cheezel choosing to actively seek approval and Max turning towards peer relationships.

The children's consciousness of others was also narrated through stories of relationships with their siblings. These stories spoke of ethics, responsibility and justice. Chontelle's consciousness extended to the impact her behaviour had on her self. She became angry at herself, "When I hurt my, feelings" and she perceived this differently to, "When I hurt myself [physically]" or "being sick" although she felt sad on all three occasions. She explained, "When I hurt my feelings. I feel very, very . . . when [Sister] hit me and I hit her back . . . I feel very stupid, like fighting . . . feel very stupid. No, [Sister] will smack me back, then [Sister] hit me and I hit her back, and I shouldn't done that, stupid. . . . But you can't do it back! Like, like. Sometimes don't, cause it's not fair, to hit the person, you don't do it back. No, when [Sister] and me, like, she hit me and I hit her back, and I shouldn't have done that." For Chontelle, hitting her sister was transgressing her sense of fairness, justice and acceptable behaviour. She had an "ethical instinct" (Frankl, 1997, p.41) that guided her behaviour with others and shaped her views of engaging with the world around her.

The children in this study were aware of the presence of differing rules of engagement within family relationships. They understood that their position as a child meant they were expected to interact within the boundaries of these rules (Minuchin, 1974). The rules imposed by adults and older siblings did not always 'merge' with the

children's own ethics and desires for acknowledgement. This dissonance may create vulnerability, if children place their knowing of themselves within the understandings of others (Moustakas, 1959).

Negotiating conflict. I asked the children about having a fight with a friend. All, except Brett, responded that they didn't fight with their friends, but they all fought with their siblings. Narratives of selfhood were expressed when the children related experiences of fighting with their siblings; they included transgressions of time and space, privacy, and the boundaries of the self. Within these narratives, the children spoke of negotiating and resolving conflict, negotiations that influenced their perceptions of themselves and the other. They sought creative ways of resolving their feelings and restoring their emotional balance.

The children spoke of fighting with their siblings as acts of resistance and the seeking of justice for transgressions. For Ian Welsh, "Sticking up for yourself" (see Chapter 5, *Courage*) extended to fights he had with one of his sisters, "Like if she, if, she normally starts chasing me and when she starts chasing I walk into there [lounge], get a pillow and just go whack. And then she's on the lounge and then I start to go ya, ya, ya. Get her." He was aware of her feelings, that she didn't feel 'ok', but didn't perceive a need to address them, "Ah, everything's ok cos I'm the one who normally beats up. I'm the one who normally wins, so nothing happens." He remained in a position of power and his own feelings were undamaged. In Max's experience, there was no need to resolve the emotions that were stirred up during fighting with his younger brother. Rather, it "Just ends."

For Ian Welsh and Max, fights with their younger siblings were experienced as

times of power. Although they were aware of the emotional needs of the other, their need to assert their dominance was far more important. For these boys, the resolution of fighting was its physical ending. Whatever had created the fight was over and relations could return to the way they were before it began.

Cheezel's friendships with three of his brothers were fraught with fighting, "[we fight] A lot . . . because we think each other is annoying." When he fought with his brothers, ". . . the elder brothers usually like doing most of the fighting yeah, like. Because they're like, well not with each other but they're like if I'm having a fight with them they're like doing more of the attack on me yeah like there's like an attacker and a defender but the defender might be real weak or it might be like an ant verse an elephant . . . but when I'm versing [Younger Brother], sometimes we both are the attacker, but usually I'm like always beating him because every time he attacks it doesn't always hurt me." Size and strength came into play with the visual imagery of the ant and the elephant, as did the image of Cheezel being alone between his older and younger brothers in his 'fight' for agency. Like Ian Welsh and Max, he expressed awareness but not concern over his little brother's feelings.

The resolution to these fights with his brothers and the reestablishment of friendly relationships was restricted to, "Well usually, we just usually, what, like walking away . . . we just, we both calm down. We just like stay away from each other for a long time." Time, distance and the absence of the other brought calm and peace. These strategies were echoed in SSS007's narrative of fights with his older sister. The only wish Cheezel had for change in his life was related to his brothers, "Turn my brothers into dancing ballerinas, or make them really kind." He desired a transformation

in the other so that fighting could be left behind.

Brett fought with his brothers, "More with them than what I fight with my friends." His instigation of a fight was usually over transgressions of his privacy or possessions. Sometimes he beat them up, but it depended on how angry he was. In order to make himself feel better, ". . . probably just tease 'em." He didn't hit anything, "I just sit down or lay down or just, be. Or ring up nan or something." Brett chose options that Bobby, Deatherford, SSS007, Cerberus and Cheezel also chose. These boys chose creative and positive options of resistance through removing themselves from the source of anger or distress. They cared for themselves through time alone during which they could release their emotions and regain balance.

For all of these boys fighting was narrated as a physical act bounded by emotion. The resolution of conflict was a 'walking away', a removal of the physical self to tend to the emotional self. Fighting with siblings was a part of life (Brannen et al., 2000), one in which the self was threatened and the need to assert the self was integral to their response. Their ability to care for their emotional self speaks of their ability to be resilient in times of conflict, to meet their own needs. Resuming 'normal' relations with their siblings also speaks of resilience, an ability to forgive by setting aside the source of conflict and regaining connection. These boys and many of the other children sought time alone in their bedroom, a place rich in meaning as a space of privacy and healing for the self within the home (see Nurturing the self, below).

Senses of injustice. Some of the children narrated times of sadness, anger and frustration when they experienced a lack of understanding from their parents. Their parents questioned their integrity and their knowing of themselves, not accepting them

as truthful and responsible. Their desires for themselves were at odds with those of their parents. Negotiation was not an option so they sought other ways of asserting and sustaining themselves.

Relationships with parents were not always sources of belonging and trust. Children spoke of their difficulties with trust, discipline, and being believed and respected. They were made very aware of their position as children, those who were power-less within the family hierarchy and would receive punishment for unacceptable behaviour within the bounds of family rules (Hockey & James, 2003). The only times Rambo was sad, "If I'm getting a smack. That's it. Nothing else." He said this as he drew a sharply pointed triangle for his sad map, a sadness that pierced his self. 'Family fight' was placed on Bobby's sad map as he said this was the last time he had cried. Lisa and Nina also felt sad when they got into trouble, disconnected from the important adults in their lives. Their sense of disconnection evoked a vulnerability of self expressed through sadness.

I asked Max what adults needed to know or understand about children. He replied, "Good question. I think they have to be like more nice to kids, like not keeping pestering them about homework. My mum does that." As we were doing our angry maps, Chontelle was open in positioning her mother as someone who imposed limits on her behaviour in a way she disliked, "When mum is naughty! She tease me! She's annoying me about, turn off the TV when I'm eating my dinner." Ian Welsh said, "Not getting my way, you can't do very much for that . . ." which made him angry. His wishes were not met or his freedom and access to play was denied, whether it was not getting a new surfboard or not being allowed to go outside after having a bath. While

being disciplined or directed, the children experienced a lack of understanding from their parents. Their senses of belonging and trust were challenged.

Ian Welsh's sense of injustice was evident when he talked about getting into trouble with his father. He believed his sisters had caused the trouble and his father's anger should have been directed towards them. "When my sister touches something and she breaks it. And then I get in trouble, and that's a bad thing. I get in trouble cause my sister did the work. She gets me in trouble. . . . My dad always calls me, thinks I'm suspect." His personal integrity was offended by often being blamed for something he didn't cause. Like Ian Welsh, Cerberus got angry when he was blamed for something his sisters had done, "Sometimes like, it, like, they [Sisters] get me in trouble." Like them, Nina experienced blame for something her brothers had done.

These children shared experiences of not being believed, of being disciplined for another's transgression, where their knowing of the truth was not accepted. These were experiences of negation of the self because their knowing of themselves was denied by their parents. Parental discipline was interpreted (Zweig & Wolf, 1977) by these children as being at odds with their ethics.

Keeta, Rambo, Brett, Bobby, Chontelle and Elliot had experienced their parents' separation. Keeta and Rambo expressed their difficulty in resolving their feelings of sadness and hurt. Keeta's parents were recently divorced and she missed her father very much. The day before our first conversation, Keeta's father had told her he was moving away from their town and she was struggling with her sadness over this news.

Rambo also talked about feelings of sadness, "I'm sad sometimes. Like when my first, when mum and dad first split up I was really upset. And every time dad dropped us

off, dropped us off, he, he used to, I used to cry when he went. And that's it. But now I know he's an idiot. Don't even care about him. He's not part of my life anyway. He never has been. Now I've realised. *So you don't think he loved you?* He did. But he's just cookoo. He's not full quid. He used to take drugs, used to. Mum said, 'Get some help', but he goes 'No, no, I'll be right'. And that's it." Rambo constructed a reality in his narrative as a way of coming to terms with his father's absence and perceived lack of love and care.

During our discussion about being brave and incidents related to his father, Rambo raised another episode, "One Sunday I, dad used to take us out somewhere, and I said I didn't want to go, so when he come back, [Brother] has a present and [Sister] has a present and he didn't get me one. And he was being slack. So I grabbed a rock and flicked it at his car. So I just got the rock and go 'whoom' and hit his light." He expressed his feelings of not being valued, of sadness and anger, through physical retaliation.

Rambo's choice to retaliate physically to his father's lack of tangible love speaks of him attacking his father's perception of Rambo's self as not worthy of love. Rambo's relationship with his mother and siblings was one of worth he experienced internally and verbalised in his narratives. This sense of intrinsic worth enabled him to express his feelings to his father (Moustakas, 1959), albeit in secret due to fear of punishment from his mother, "Sometimes I don't let my mum know. Cause I know I would have got in trouble." His narrative of his father's reasons for leaving the family removed any doubt in his own mind of his self-worth (Rogers, 1961). For Rambo, it was his father's self, not his own, that was questioned and found wanting, sustaining his resilience to the

feelings of rejection he had experienced (Fine, 1991).

For all of these children, senses of injustice were experienced through parental discipline and emotional distancing. Children internalised their perceptions of injustice, which created anger and sadness. These feelings in turn created a vulnerability of self that some children resisted through positioning parents as at fault. For other children, knowing there was little they could do to alter a situation caused an emotional withdrawal, in order to protect the self (Moustakas, 1959).

Acts of courage. Times of danger and acts of courage were narrated by children in relation to threats upon themselves and those they loved. They needed to draw upon their courage to seek the support of others. Even though the threats came from adults they did not hesitate to respond to protect themselves and their family. Elliot, Rambo and Groovy Princess narrated stories of courage expressed through facing danger and refusing to allow the self to be overwhelmed or controlled. Their courage was called upon in extreme circumstances of need; they knew it was already present within the experience of their lives (see Chapter 5, Courage).

Rambo had told me a few times that he didn't get scared, prompting me to ask him whether he got scared of anything. He replied confidently, "I've never been scared." He then conceded, "Oh one thing. When my dad was, he was drunk right, and then he come into our house and he wasn't allowed near us. That was scary. *So was he really angry and stuff?* Yes. He's a nut." He then returned his attention to his drawing, closing the matter. In our third conversation when we were discussing courage, his mother raised an incident in relation to his father. She told Rambo he was very brave when he went into another room and rang the police, "I hit him in the leg and ran into the room,

and rang [the police]." Rambo admitted he was scared when this happened, "I was. I was shaking like this. *So how did you still get yourself to be brave and do that and go and ring up?* I just crawled into mum's room and then when the police answered the phone I calmed down." Despite his fear he was able to act in order to gain outside support.

Like Rambo, Groovy Princess chose to act when her mother had been threatened by an extended family member, "My mum thinks that I'm a really brave girl too, cause I, like I saved us all, by ringing the police. I was real scared and I was crying when I was talking to the police." Even though Rambo and Groovy Princess were very afraid, they became the protector and saviour of their families. They sought to protect their mothers and siblings, rather than expecting protection from their mothers. They saw themselves as capable of protection even within their fear. They were not victims of circumstance, rather makers of an alternate reality of children with disabilities as resourceful and possessing an emotional strength that could be called upon in times of need. Their mothers' affirmations of their bravery deepened their sense of themselves as capable and courageous.

Elliot had been sexually abused by an extended family member and was bullied at school (see Chapter 7, When people are mean). He wanted to make a stand. "I just get really annoyed with them cause like I'm annoyed with what happened to me, involved with like [Adult] and all that. I'm really upset. I just want to get back at [Adult] in some way. Like ever since that happened, what [Adult] did to me, like I've been really annoyed like with like people bullying me. Like I just won't take it any more. Like I can't stand it. I can't stand it. I'm really annoyed. It's reached my limit now. It's time

for me to just like take some action." Anger, frustration and the desire for justice were strong in his voice. He was building courage and setting his boundaries so that he would no longer accept the role of victim (Polkinghorne, 1996). He believed he had been extremely brave when he had to deal with the abuse situation, telling his father and the police, thus changing his understanding of himself to that of an agentic player in his own life.

Elliot's philosophy of courage was bound within his relationship with God, "Well courage means being brave and just getting through things and getting over the bad times. Just getting on with your life. Well, I think God gives me the courage and it goes in my heart and then I believe in God and then I just have courage." Like his family shield and his knowing of resilience (see My shield, above) courage was received from another and internalised. He was able to draw upon it in times of need.

Children with disabilities are not commonly perceived as protectors of others or as children who may choose to protect and fight for themselves. The extreme, but not uncommon, circumstances of violence and abuse (Mulrone, 2003; Westcott & Jones, 1999) these children shared with me, spoke of their emotional strength, their resilience, in meeting and dealing with very real danger (Fine, 1991).

Being trusted. All of the children perceived themselves as trustworthy. This knowing of themselves was reinforced by parents; who asked them to help care for younger siblings, enabled them to make their own choices, and expected them to be responsible in caring for themselves. How the children perceived the trustworthiness of family members was often based on experiences of placing trust in another and that trust being honoured. Parents were usually trusted, the children were able to set aside their

experiences of not being heard or respected in the course of everyday life. Siblings were often not trusted and this was usually based on experiences of siblings' dishonouring their privacy or behaving aggressively.

Brett and Lisa narrated experiences of being trusted by their parents. For Brett trust meant, "It means you have to be, well you have to be reliable, responsible, you have to be trusting, yeah. You just have to be . . . good and, you have to be, you have to prove that you've been good before, so that then someone can actually trust you to do something for them. *So can you tell me a story about trust? Or like a time when someone's trusted you or you've trusted somebody else?* Oh well dad trusts me just, because, when we're on holidays since, well, I don't know, I think I'm old enough to look after myself. Dad, well, he trusts me and [Brother] I suppose, to look after ourselves on holidays cause he's at work, we're usually at mum's. But then I am also trusted there again, to, to make sure that [Brother] doesn't get in trouble cause he's in that stage of life, at the age of 13 and 14. So dad trusts me to do that." This represents a reversal of traditional roles with the younger Brett being the guardian of an older brother, being trusted to be responsible, to keep his brother from harm.

I asked Lisa whether I could trust her and why, "Yes. Because everybody trusted me once, I'm the only one that remembers things like from when I was two so they, my mum and dad, trust me to remember." She was trusted with the family memories, becoming the keeper of family history. Both children were trusted by their parents and had shown themselves to be trustworthy. The trust received from their parents strengthened their sense of knowing themselves as trustworthy (Moustakas, 1959).

The children were definitive of their trust in others, choosing to place their trust

in those who had shown themselves to be trustworthy. They chose to place their parents and friends on their trust maps, and sometimes their siblings. Elvis and Lisa had similar views on trust. Trust to Lisa meant, "That means . . . they're a good person. Like if they help people." She explained further by saying, "[Sister] helps people if you ask her." Lisa said, "I trust my mum and dad." But this unqualified trust did not extend to her sister, to whom she extended a qualified trust, "I sort of trust [Sister]. [Sister]'s cheeky sometimes." Lisa needed to be careful with the secrets she shared with her. She did not trust her brother, "Na, he's really mean sometimes." His 'meanness' of spirit caused her to withhold her trust. Her trust was a complex decision based on a range of others' behaviours experienced over time (Bronfenbrenner & Morris, 1998).

Trust for Elliot meant having someone he could count on, someone who would help. "Trust means being able to . . . look up to someone when you're hurt. To help you through the bad times." He spoke of his need to trust that his father would believe him about the abuse (see Acts of courage, above) and would do something to help him. He considered trust to be both an internal and external feeling, "I think both." To explore this further, I asked him what he thought it would be like if you couldn't trust someone, "Well, you'd feel empty inside. You wouldn't know what to do in your life. You wouldn't know what to do if you got hurt. You wouldn't know what to [do], who to turn to." Elliot's narrative spoke of the emotional devastation an inability to trust another could engender in the self, and the strength of his need to have another to trust. For Elliot, trust was woven into the foundational security of life, with an absence of trust making his identity vulnerable and making him feel separate from the world (Moore, 2002).

Children with disabilities are unlikely to be cast in the role of those who assume responsibility. Parental trust positioned these children as active contributors to the family welfare, taking on roles traditionally expected of older children or adults. Their parents affirmed the children's knowing of themselves as responsible and trust-worthy (Moore, 2002; Moustakas, 1959; Rogers, 1961). Who and how children trust have implications for understanding the ways in which children relate to their family. There cannot be an assumption that children automatically trust their family members or trust them in similar ways. These children highlighted their understanding of trust as a giving to the other of the self, enfolded with being cared for and honoured. If this giving of the self had been challenged in other aspects of their relationship, then the ability to trust the other became qualified.

Rhythms and Rituals

Family rhythms and rituals gave purpose to the children's activities within the home. The rituals provided a framework within which children could help their parents and be part of the family world. Selfhood was expressed through the sameness of being a child within the family, influencing the construction of identity. The shared meaning of chores, leisure activities, holidays and celebrations contributed to the children's sense of belonging and being loved, and gave them avenues of offering these qualities to others. Rhythms and rituals were an enfolding of self and others within shared meaning. Within the family, children also sought to create their own rituals where they cared for themselves through time spent alone. In these times children immersed themselves in activities that nourished their spirit.

Family work. Children's sense of self was fostered by contributing to the family work, developing their consciousness of the needs of others. Brett helped his parents with the daily chores, contributing to the lives he led in both homes. Helping his parents had purpose and gave Brett opportunities for agency, "Oh well, we usually, go down to dad's work on the weekends when he's there, or when, like in the afternoons and do all this filing on his computer for him. Answer the phones and stuff. I fold up the clothes and that for dad and mum." His work with his father gave him adult responsibility. When I commented that his father must trust him "a fair bit", Brett straightened and smiled, with a look that said to me he hadn't thought about it that way but it felt true and pleased him.

Chontelle's regular contribution to the family work was, "... cleaning the table [after dinner]." A job she alternated with her older sister. This did not seem to have personal meaning for her within the rhythm of family life; it was a 'chore'. However, she considered it to be a way of helping. For Chontelle it had known meaning through its importance to her mother, and she accepted that it was not important to her. Her sense of responsibility came from her commitment to her mother, someone she loved (Frankl, 1959).

Ian Welsh and Rambo did not see contributing to family work as purposeful. They experienced it as an infringement of selfhood. Ian Welsh felt angry when, "Having to do something boring." 'Something' with no felt sense of purpose, such as "Setting [the] table." In contrast to Chontelle, he did not find meaning through contributing to the family work. Ian Welsh's displeasure with chores was echoed in Rambo's comments, "Chores, they're like jobs. Doing around the house. But I get five bucks if I do it. I still

hate it but." For Rambo, chores accompanied by payment did not alter their intrinsic meaning as burden. For these two boys, chores were an imposition, reinforcing that they were expected to contribute to the family work, but in ways determined by their parents not by themselves. They were expected to respond to adult authority and sublimate their own desires (Mayall, 1996).

Groovy Princess also had chores to do at home, "But it's all right though. Most of them are fun kind of jobs, like doing the animals. It's good just to give them like a nice pat and play with them while you're feeding them as well. I'm more like an inside person though. Most of my family likes being outside. . . . The only reason I really like being outside is playing on the trampoline or sitting in the sun or playing with my animals." Groovy Princess's chores enabled times of connection with her loved rabbits, giving these chores a sense of play rather than work. Her narrative also spoke of her understanding of her difference within her family, through her desire for 'inside' time. This difference was spoken of in a way that was an acknowledgement rather than a difficulty or sadness.

Like Groovy Princess, Michael Jackson found pleasure in the sense of belonging that arose from helping at home, "And I like my, washing, helping my dad washing the car. I did it with him last weekend." These were times of joy and sharing with his father that, like Groovy Princess, made chores a pleasure rather than a burden. For these children, play and work were enfolded (Parham, 1996). Michael Jackson shared Groovy Princess's preference for being inside. The joy and belonging experienced through these chores enabled them to extend their boundaries of meaning to areas outside the house (Rowles, 1978).

All of these children saw chores as either a burden or pleasure through which they were expected to contribute to the family work (Larson, 2004). Elvis didn't contribute to family work, being positioned as dependent within family relationships. He was the only child who spoke of chores being related to his disability, "... go in my standing frame . . . and my Hart walker." He spoke of them as being unpleasant and a burden. The Hart walker made him feel physically ill, but "... don't really do anything about it." He tried to avoid it rather than seeking to change it. His comments spoke of a lack of self-agency; he felt unable to change what was happening to him, echoing the powerlessness he voiced in his desert narrative (see Chapter 5, An Alterity of Being).

Larson (2004) posited that children with disabilities who did not contribute to family work may have relationships with family members where they are perceived as less capable. These interactions may lead to dependency and 'learned helplessness' (Seligman, 1995). In Elvis' homeworld, his dependency appeared to weave into his perceived inability to be his own agent of change (Polkinghorne, 1996), a vulnerability of self within his daily routines of managing the self.

Leisure. Children had moments of connection and shared pleasure when they participated in leisure activities with their families. Family and friends were important in Elvis' life, "Family, and my friends, I don't care about anything [else] much." Not 'much' else mattered to him outside of these relationships that gave love, care and value to his being. Elvis found moments of togetherness with his family, sharing a common pastime, "I like the one's [TV shows] at night. We watch them together." Cheezel connected with his father and brothers by playing chess. Max, Brett, SSS007, Deatherford, Barney and Cerberus connected with their fathers by fishing or

participating in water sports. Lisa had shared the pleasure of horse riding with her mother and brother. These times of shared leisure activities were important times of being with the other. The children could be enfolded in the family circle, in which meaning was shared and relationships deepened. Being within the flow of the activity enabled positive connections with their parents and siblings (Humphry & Case-Smith, 2001).

Bobby and Deatherford shared their parents' pleasure in bike riding. Bobby's choice to make a bike with pipe cleaners reflected his pleasure in his own bike and in riding with his mother. Deatherford told me a story of being on the back of his father's bike when the family visited the Dubbo Plains Zoo. He then let me know, "So, but I know how to ride a bike now. . . . I learnt to ride a bike, from the most awkward time, like my dad, had taken my bike down to my old school, about very early last year, 'bout still during the holidays last year, and, he took me down and then we just started, just started, somehow I just started riding . . . just like that, without my dad even having to give me a push. I just started going . . . I just didn't, I wondered how I had done it, like I kept on riding round my mum and dad, like circling them." This was a story of wonder at unexpected mastery. He no longer needed the help of his parents, rather 'circling them', showing his skill and independence. Deatherford could then actively share in the family activity rather than being a passive participant. He experienced a rite of passage (Hockey & James, 2003) and a moment of transcendence (Moore, 2002).

Celebrations. As we did happy maps, all of the children spoke of the celebration of their birthdays as a time of happiness, and of being valued and loved. Many children spoke of this occasion as one of the 'special things' that happened in their lives. Several

children included Christmas and Easter on their happy maps. These were all occasions of being with others within times of significant meaning.

Elliot spoke of the special times in his life, "Oh some of the special things are like I get to go to parties. My birthday is never cancelled. And like I can go to movies sometimes, and I always enjoy myself, and I think they are the really special things that we should be grateful for." Birthdays had additional meaning for him, "A really happy time in my life is when I have my birthdays cause I get lots of presents and I'm, and I get the most attention. And I get to do anything I like. That's the day when [Elliot] rules. Yeah and I can go wherever I want." For him, this was a day where desires could be unfettered from everyday restraints. Elvis suggested that the celebrations of birthdays, Easter and Christmas deepened his sense of connection with his family.

The children shared the joy of their being, through their birthdays and participation within the wider communities of culture and religious faith. Christian celebrations were times of sharing joy with family through cultural meaning. Celebrations contributed to the creation of identity as a child within the family.

Children are enfolded within family life, through responsibilities, leisure pursuits and celebrations. Family rhythms and rituals provide important continuity and repetition, laying down of a sense of self over time (Bronfenbrenner & Morris, 1998). Children's identities can be constructed as contributing members of the family, valued and valuable (Brannen et al., 2000; Mayall, 1994). For Elvis, Ian Welsh and Rambo participating in celebrations gave a sense of being valued, but engagement in chores brought a sense of restriction and burden, where the self was expected to be compliant (Mayall, 1996). The different ways children experienced family rituals and rhythms

highlights the importance of leisure activities, celebrations and the ways in which they may perceive their contribution to family work. These activities may engage children within the family or lead to a sense of disengagement with the self and others.

Nurturing the self. All of the children spoke of ways they sought to nurture themselves within their home world. They created their own rituals of meaning, separate from but embedded within the family culture. They sought times in which they could be alone to regain their emotional balance (see Negotiating conflict, above), or to immerse themselves in creative expression. Reading, listening to music, drawing, painting, and being in nature were all times of spiritual reconnection and restoration of the self (Christiansen, 1997; Moore, 1996). These and other activities, such as shooting hoops, also gave moments of mastery and agency, or times of imagining the self as other. Many activities took place within their bedrooms, which were private spaces decorated with items of meaning: pictures, books, CDs, trophies and toys. Their bedrooms were spaces of expressions of the self (Rowles, 1978), their past, present and future identities (Rowles, 1991).

Reading was a time of nurture for many of the children, enabling them to immerse themselves in other worlds and to imagine themselves as another (see Chapter 5, Part of the story). This time of stepping away from reality also enabled them to recover emotionally from fights with their siblings. For example, SSS007 found solace in reading Bible stories. He particularly liked to read the story of his name saint (see Chapter 8, A source of support), and it was especially valuable when he had been fighting with his sister.

Children also chose other activities to nurture themselves. Cerberus talked about

what he did when he was 'unoccupied', "When I don't got nuttin' to do I just think. . . . Well, with the picture I think about, like, how I'm gonna do the picture and like, that." He designed scenery for 3D models, "Well, like, once saw a dinosaur, like, the painting, not. Well, we made rocks and a waterfall, volcanoes, dirt. They're all in my room. And, like, but, before, like, I got what else to do it, like and we use some of the craft things. Like toilet rolls or. Make, like make trees, or make logs, or make volcanoes. Bark, from outside. I did find some bark, did collect rocks from my nana's. . . ." Cerberus expressed his creativity through constructing other worlds that he could bring into his world. These projects often became a shared ritual with his mother because he needed her physical assistance.

Groovy Princess told me, "Normally I do lots of dancing and singing during the weekends and things and I like having friends over and we always dance and sing. And I went to my friend, [Friend's] place one weekend, and we did, we had my CDs and we just danced and sung most of the weekend. . . . I just like it because it's not really, like it's a kind of thing you can do but you can also do it any way you want." These were times of creative expression, a transcendence of self (Graham, 2002), which she enjoyed alone and with friends. Dancing and singing met her preference to be inside (see Family work, above) and she could live out her desires for the future (see Chapter 5, When I Grow Up).

Michael Jackson found joy through his love of music. In our first conversation he initiated a discussion of music and singers, and during a later conversation he asked me to take a photo of him with his favourite albums. Michael Jackson listened to music, ". . . just usually when I'm bored. Yeah, cause there's nothing to do." Music gave him a

way of regaining meaning when times were purposeless or he had no-one to share them with. He also liked his PlayStation™, "Watching television. Looking at the pictures on the wall." His grandfather was a professional photographer and there were a number of family photos on the walls. For Michael Jackson, home was a place embedded with meaning (Rowles, 1978), "My whole house makes me happy."

When he was outside, nature made him happy, "Outside the house, I think it's the view. And it's like beautiful, beautiful grass, beautiful air, and you can just look at the sky." Ian Welsh shared his awareness of nature and the joy that it brought. Being inside made Michael Jackson the happiest, "But being happy makes me most happy, being inside. I like inside most of the time. I don't go outside a lot." Michael Jackson and Groovy Princess had constructed rituals that met their desires to be inside.

In his room, Elliot daydreamed when listening to music, "Like sometimes when I listen to music I shut my eyes and just see myself riding on a scooter or skiing down the slope or something. Just see visions of myself doing things." Sometimes he daydreamed about doing things he would like to do, "Like, doing a high jump or something." In his daydreams he could project himself into a space of physical risk, where in daily life he wished to go. He added, "Wishing like I can't do yet but I'd like to do." In these times, he could imagine transcending his physical self.

Lisa's love of horses had remained even though her family now lived in the city, "For my birthday I wanted a horse, even for Christmas I wanted a horse. Well I like to go to horse riding lessons and my mum said we'll see so we might find out where they are but I don't know." To meet her own need for connection with horses, Lisa read books and watched TV shows about horses, and, "... sometimes I play with my sister,

horses yeah." These activities enabled her to imagine being with horses, as she had done in her drawing (see *Pets as Family*, above).

For the children in this study, reading and listening to music gave times of stepping outside reality and imagining being another. Their artistic expression gave ways of expressing their creativity and building other realities. All of the children spoke of activities that brought purpose and joy. By engaging in these activities, the children enabled themselves to replenish their spirit (Hasselkus, 2002; Moore, 1996).

The children who participated in this research expressed their understandings of themselves and others, and their desires for selfhood and sameness within the family. Narratives of the children's home worlds reflected the meaning of important relationships with parents, siblings, extended family members and pets. Home was experienced as a place of negotiation and conflict as well as a source of belonging and expression of the self. As a space of creativity and a place of responsibility, it was a rich and, at times, demanding world that shared in the creation of their identities. Children spoke of home as a place of protection and respite from the outside world. Although it was not always a place of safety, with children experiencing threats to their safety and the safety of others, it was always rich in meaning. Their being within the emotional contexts of home and family was a source of identity (Rowles, 1991).

Implications for Practice

It is within families that we learn how to be in the world – how to understand and interact with the world and the people around us.

(Fitzgerald, 2004, p.489)

Occupational therapy's interest in children's home worlds has traditionally focused on functional skill development (Case-Smith, Allen & Pratt, 1996; Kramer & Hinojosa, 1999). Recently, there has been a development of interest in family routines

and rituals (e.g., Case-Smith, 2004; Cronin, 2004; DeGrace, 2004; Kellegrew, 2000; Segal, 2004). However, this interest has been confined to the perceptions and needs of parents, remaining focused on the impact of children's impairments on family life. Children's influence on the family world and relationships is given voice by parents and professionals. If we wish to position children within a more active model of reciprocity, there is a need to understand children's contributions to family life beyond aspects of 'doing'.

For all children, expressions of selfhood and sameness are lived within the lifeworld of home and family, expressions shaped through love and the challenges of negotiating relationships (Ricoeur, 1992). Children's identities are re-formed by the repetition of experiences through family relations, rhythms and rituals (Bronfenbrenner & Morris, 1998). Their identities are shaped by their sameness as a child and sibling, subject to family mores, discipline and responsibilities, and by selfhood created through desires for agency, negotiating conflict and caring for the self.

Within our relations with families, we need to look for the unique ways in which children interact with others. Children's interactions are not only an expression of identity but a means of sharing the self. In this study, children sought to give and receive love and belonging, through art and voice, and the embodiment of compassion, hope and faith. We need to create spaces in which children feel comfortable about expressing their values and opinions so that their identities are not bound by cultural scripts, but are able to challenge these understandings. We will be enabling children's identities to be heard.

We need to design our interventions based upon the needs and desires of both parents and children, to enter the dynamic of their relation and negotiate within it. If we

appreciate the dynamics of these relationships as they affect children, it will bring an awareness of their meaning in individual children's lives. We will have a greater understanding of how identity is created and intertwined in these foundational relations between self and other. We need to be aware there may be differences in the way children and family members wish to engage. We should explore with children how they wish to negotiate with others in order to meet their own needs and maintain their sense of identity. Doing so will contribute to the fostering of engagement through respect, contributing to children's resilience.

When designing family interventions, we need to remain aware of the emotional ambiguity of sibling relationships. In my research, it was important for the children to determine the level of involvement of their siblings. Although we may wish to include siblings in intervention strategies (Anderson & Schoelkopf, 1996), children may wish to retain their space and privacy. Alternatively, inclusion of siblings may facilitate skills of independence in ways we had not imagined, for example, through caring for another (Brannen et al., 2000). We need to pay attention to the fluidity of sibling relationships, noting when children wish to be with their siblings and when they do not.

In considering the family, we need to include pets as members of children's families. Pets need to be considered as more than a source of enjoyment. We need to ask children about their relationships with their pets and to consider including their pets in therapy interventions. Children's pets can serve as a very powerful source of comfort and encouragement during difficult times that may include mastering challenges or persisting with painful treatment (Velde, Cipriani & Fisher, 2005). The kind of relationships children have with their pets may indicate the relationships they wish to

have in other domains.

The children's narratives ask us to consider the importance of self-constructed rituals that may or may not be enfolded within family rituals. Within our practice we need to consider how children are caring for themselves through their rituals, through the choice of activity and the way in which it is enacted. In our construction of intervention strategies within the home, we need to embed the times children need for themselves. By respecting children's needs, we will be enabling their ability to continue engaging in family relationships and routines. If we fail to take these things into account, we run the risk of disrupting existing ritual structures and modes of communication.

This research highlights the need for occupational therapists to reconsider the fluid and dynamic nature of all family relationships. Children's resilience is contributed to through what they receive as well as what they give within these relationships (Mayall, 1996; Merleau-Ponty, 1962, 1964). Within this co-construction of the nature of 'family' (Hockey & James, 2003; Mayall, 1994) spiritual qualities are offered and evoked (Coles, 1990; Hart, 2003). This spiritual environment enables children to build their resilience. These qualities support the ongoing creation of identity, one that will be carried into other relational contexts. A focus on these aspects can help to shift the functional focus of occupational therapy intervention, to one of supporting reciprocal relationships that contribute to the creation of children's identities as resilient and active beings.

Chapter 7: Spaces of Learning

On entering the social world of the school, children have to acquire, work on and develop another identity – that of schoolchild.

(Mayall, 1994, p.118)

Occupational therapy's role within school settings is to enable the participation of children within "the least restrictive environment possible" (Mulligan, 2003, p. 115). Understanding the power relations that impact upon children's desires to participate at school will enable us to identify the affordances and barriers that exist within school cultures. Listening to children's voices within the contexts of their school world enables us, when determining educational goals, to consider what holds purpose and joy for children. Children's desires for participation and how they wish to achieve them are integral to the implementation of plans for their engagement in the occupational role of student.

Currently, occupational therapy perspectives of children's roles within school are largely focused on the development of the functional skills needed to enact these roles (e.g., King et al., 1998; Mancini & Coster, 2004). Our understandings of the shaping of identity within school relations are limited. Recent occupational therapy research has begun to elicit children's voices in their desires for enabling relationships (e.g., Hemmingsson, Borell & Gustavsson, 2003; Skar & Tamm, 2001) and environments (Prellwitz & Tamm, 2000). This research is a positive step towards children speaking for themselves, and an alternative to adult understandings of their lived experiences being heard. Entwining children's perspectives with the perspectives of adults (Pollock & Stewart, 1998; Segal et al., 2002) and peers (Tamm & Prellwitz, 2001) will create a

multi-dimensional understanding of school life. Such an understanding will enable us to be more effective in our evaluation and intervention in this setting.

Social and cultural influences are enacted within the school world. These influences may support or challenge children's self-expression. School may be a space of exploring selfhood, through the purpose and joy found in learning. Children may experience a sense of belonging through friendships and participation in the daily relations of school. Alternatively, school may be a space of isolation, where selfhood is threatened through bullying and rejection. As a space of isolation, children need to draw on their courage, to sustain their compassion for themselves and others, and to believe in their alterity of being as value-full. School experiences contribute to the creation of children's identities within their occupational roles as students, peers and friends.

This chapter explores children's relations within school settings from their perspectives. Their experiences of policies, learning, teachers, peers and friends are considered within social and cultural expectations. A deeper understanding of the agency of children within this context is made possible by knowing how spiritual qualities are embodied and evoked within these relations.

Changing Spaces

The children in this study participated in a diversity of school environments (Appendix M). They talked of the effects of educational policies on their lives in relation to where they could go to school, and the support they were likely to receive. They spoke of their awareness of their separateness from other children and how, at times, it was reinforced by their teachers. Spaces of inclusion and exclusion were experienced between and within contexts.

Brett attended a Catholic primary school. He was very aware 'the government' should provide what he needed at high school, telling me he was originally going to a Catholic high school, but ". . . they couldn't, they would not have to supply this stuff [computer] for me." This equipment was essential to his learning. As a result, he couldn't go to the high school where most of his classmates were going. Educational policies were separating him from the world in which he wanted to belong.

Chontelle experienced a strong sense of otherness at her previous partner school, "Mum, remember last time I didn't have my implant on"? Her mother told me Chontelle had not been allowed to wear her cochlear implant in the school class photo. She had been told to remove it before the photo was taken. Children who wore glasses had also been told to take them off. This school acted out their desire for childhood homogeneity, denying difference rather than honouring alterity.

As we looked at her current partner school class photo Chontelle exclaimed, "Look, I had my implant in". She said in a later conversation, "[Previous Partner School] didn't like kids who were special, but [Current Partner School] does." Chontelle's narrative is a reminder of the power of the societal (and very personal) positioning of children with disabilities by adults, and how this can be reflected in a class photo (Reeve, 2002). Limitations still exist within mainstreaming policies. The need remains to change the culture of schools to become inclusive spaces, in contrast to symbolic moments like this in which difference as abnormality is reinforced.

For many children, being placed in a school for children with special needs, whether a separate establishment or a special unit within a mainstream school, reinforces the medical model categorisation of disability. This model emphasises a

medical otherness that is 'treated' and responded to differently from the needs of other children (Davis & Watson, 2001). The enactment of this model reinforces in children's minds that they do not belong within the world of school children except with the permission of adults. Although policies may enable 'belonging', practices may be still be conditional, as experienced by Brett and Chontelle.

The powerlessness of children in school creates a vulnerability of self that may only be overcome through the power of adults (Fattore & Turnbull, 2000; James et al., 1998; Mayall, 1994; Moss & Petrie, 2002). The construction of disability as otherness is enforced through environmental and social barriers to children's participation. Being positioned as other could cause children to attempt to make their needs invisible in order to belong (Maslow, 1999). However, Brett and Chontelle chose to continue to draw on their faith in themselves, continuing to express their right to be. They resisted the production of otherness being made through educational policies that positioned them as less valuable than their peers.

Times of transition. Many of the children had changed schools. Sometimes this was because the family moved or parents sought better services, but often it was due to difficulties children were experiencing because of loneliness or bullying. Their narratives of these experiences spoke of challenges to their identities through relationships of belonging. These turning points in their lives often brought moments of transcendence. They became opportunities to transcend identities imposed by others, of aloneness through difference. Children gained spaces in which they could express themselves in relation with others.

Although school transition is perceived as a stressful time for children, Bobby,

Groovy Princess and Nina experienced it as leaving behind loneliness and entering spaces of belonging. Bobby had no friends at his previous school, "I had no friends over there I think." He agreed having friends at his current school made him happy, yelling into the microphone, "VERY HAPPY." Groovy Princess had changed schools five times in four years. The changes in schools had been partly due to family moves but there were two occasions when school changes occurred due to a lack of friendships.

For Nina, transferring into her current school had been difficult, "I couldn't find friends. And then this year I made a lot of friends." Her difficulties with Maths (see Narratives of Learning, below) concerned her greatly because of the looming consequences, "I think I'm repeating Year 4. Because they're thinking about repeating me . . . because I still don't know my times tables. But I don't want to be, I don't really want to repeat. Because I won't get to see my Year 4 friends." Later she told me that at her previous school she hadn't had any friends. The possibility of this experience recurring in her life preyed on her mind. She was not being consulted about repeating and could only wait upon the decision of adults who were focused on her academic performance.

Brett and Michael Jackson were facing significant changes in their school life. Both boys were going to be changing their school identities and their known environments as they transitioned to high school. Due to his visual impairment Brett needed to 'learn' new environments. Knowing he would have his two best friends with him at high school helped to ease his concerns a little about getting visually, and literally, lost. One of his brothers attended high school and the relationships he had established would help Brett to form new relationships and create a new identity as a

high school student (Brennan et al., 2000).

Michael Jackson attended a Special Education Unit within a mainstream primary school. He was concerned about changes that were going to happen in his school lifeworld, "Next year's my last year here. I'm going to miss it." A turning point was going to occur in his life, which made him sad as he would no longer see the friends of his childhood, "Yep. I'm going to miss my friends. That's why I'm asking for a copy of my first photo of the dress up parade so we don't forget each other when we leave." The strong bonds of friendship and belonging were going to be broken.

A more immediate concern for Michael Jackson was moving into the mainstream public school the following year, in preparation for his attendance at a mainstream high school. In our last conversation he let me know he was very unhappy with the thought of being mainstreamed. He told me he didn't like "them" (the mainstream children) and "they" didn't like him. He spoke of how 'they' treated him as different and he wasn't, he was the same as 'them'. Societal positioning was established through school policies of educational separation and enacted by other children through social separation.

Michael Jackson's narrative of mainstream students contained an absence of shared spaces or activities that may have promoted attitudes of understanding and inclusion. This situation serves as a reminder to those responsible for designing services to implement transitional strategies with all students. These strategies need to build positive perceptions of children with disabilities, so students and teachers are inclusive in their attitudes and behaviours in the classroom and playground (Hurley-Geffner, 1995; Townsend, 1997).

Transitioning could be experienced as a positive or negative experience.

Although moving to a new environment elicited anxiety, the negotiation of relationships with peers was foregrounded by the children in my study, as it was in the study by Pratt and George (2005) of children without disabilities. Children in both studies spoke of the importance of being able to form and maintain friendships. Friendships offered a sense of sameness, a belonging within a community of students.

Friendships also offered help in times of need (see Being a friend, below). The loss of friendships and the threats of aloneness and vulnerability were significant issues for many children, foreshadowing a loss of continuity, of being known and accepted by others. Children would also experience a loss of a context or community in which the sharing of spiritual qualities of love, trust and compassion could occur everyday. Schools that are enjoyed by children work to actively create a culture and sense of community. This is reflected in the children's narratives of desires for connection and continuity, and brought into sharp relief by the inevitability of leaving.

Adults involved in supporting children with disabilities when they transition to new schools, or new school environments, must remain aware of the importance of friendships within their planning (Pratt & George, 2005). Children need to be supported in dealing with their sadness of the loss of friendships, enabled to maintain friendships where possible, and supported to form new friendships (Brannen et al., 2000; Shaw, 1998). The significance of friends and older siblings providing practical and emotional support (Lightfoot, Wright & Sloper, 1999) draws them into an important role in the planning process. A child's identity is tied up with a school identity within a larger

community of students (Mayall, 1994). Maintaining friendship connections is crucial for positive transitions.

Part of the group. All of the children participated in extracurricular activities of sport and excursions. For most, these activities provided experiences of belonging, where they were part of the larger group and enfolded in enjoying the moment. However, children did experience times of being isolated through the constraints of their impairment and the disabling conditions of school cultures and environments that did not provide inclusive opportunities. Where schools did not adapt activities so children could participate, they were left as passive observers of other children's shared pleasure and their own exclusion. Opportunities for social relations with peers (Poulsen & Ziviani, 2004; Shevlin et al., 2002) were lost.

Cerberus narrated two stories, one of belonging and one of exclusion.

Participating in school sports activities gave Cerberus a sense of belonging within the school culture. He had participated in "Cross country! A running race." He had two children with him and was allowed to take a short cut, but "They didn't tell me like where to go. Like I did came. I did come third last year. . . . Like, like, you only get ticket for first, second and third. But I, I did get one. Instead of stayin' home and just doin' nuthing." Through his choice for engagement he had created a physically active identity. His desire to win another 'ticket' was evident in his voice and this motivation had overcome any reservations he had of not participating. His school was attempting to meet his needs within their policies by accommodating his embodied difference.

In his second story Cerberus spoke of a school trip to the city's aquarium. He considered it a memory of mixed emotions, "Well, it was pretty happy and it was then

not happy." Within this memory were difficulties with access to areas of the aquarium, "That man, he got a ramp up but I can't get down to 'im." This experience had changed his desire to participate, "I'll never go no . . . none on the excursion without mum. Er . . . dis accursion, I didn't like it at all [because] I couldn't go down [to where the other children were looking at the fish] and . . . All I wanted to [do]."

This excursion could have been an experience of independence from his mother, simply being another student in the group. Unfortunately, it was not supported by the community environment or by school policy. He was returned to dependence on his mother to carry him into wheelchair inaccessible areas. Although he was included in this excursion, it was a limited inclusiveness. The environmental barrier excluded him from belonging with his class. He was excluded from engaging in the meaningful activity of observing animals, which was enfolded in his desires for the future (see Chapter 5, *Becoming*). This experience also challenged his trust in taking risks through engaging in new leisure and community experiences (Giddens, 1991), thus limiting his imagined freedom.

Environmental barriers at school and in the community need to be addressed so that children are not passive observers (Doubt & McColl, 2003; Poulsen & Ziviani, 2004). As highlighted in Cerberus' narratives, there are degrees of inclusiveness (Shevlin et al., 2002). Enabling environments that support the needs of all children will promote a school community based on independence and interdependence (Gleeson, 1999). Discussing with children the ways in which they want to participate is an initial step in enabling them to engage in extracurricular activities. From their views, adults and children can co-construct ways to enable their identities as a full member of their

school culture. Full inclusiveness will enable a greater sense of belonging through social interaction (Doubt & McColl; Staub, 1998).

Narratives of Learning

I asked the children what they liked 'most' and 'least' about school. Their replies were often related to learning, which merged with my question of what they liked to learn. All of the children were definite about their favourite and least favourite subjects. The reasons they gave related to perceived competence, connection with desired future occupations, and their ability to express their creativity. There were children, like Elvis and Lisa, who replied that playtime was their favourite time at school, foregrounding their desires for friendship and freedom from the constraints of the classroom.

Learning new skills and being recognised for their mastery was important to Bobby, Brett, Ian Welsh, Deatherford and Cheezel. Bobby's favourite learning at school was, "Ah, let's see, workbook. Cause I get a star. Get lots of stars for English, and I already have English. I haven't got science, got science." He went on to say he didn't really like science or English, but did like maths. The stars in his workbook gave external reinforcement of his effort and worth as a school student, which were important to him despite his preferences for learning.

Achieving at school was also important to Elliot. Each week he would share with me the perfect scores he received on his spelling tests. When I asked him what made him feel strong inside, he replied, "What makes me feel strong is like getting on top of work, completing spelling tests." Achieving within the world gave him emotional strength. However, when he didn't master spelling words or other tasks he became very distressed. Mastering the challenge seemed to mean more to him than the joy of learning

or discovery. His focus on mastery left him with a vulnerability of self, which was only relieved when he achieved his goal.

Nina and Rambo shared a love of handwriting and a dislike of maths. Their perceptions of their struggles with maths contributed to a sense of incompetence, of being lesser than their peers because of cultural expectations of finishing on time and not being bottom of the class (James et al., 1998). For Rambo, these cultural mores were enacted through teasing by his classmates. On his angry map Rambo placed school in general, "Okay. School. Yeah, I hate school. School. It's just boring stuff. *So you're not learning things you'd really like to learn about?* No. Why can't we learn about motorbikes or stuff like that? We learn about maths. Maths is motor bike you know, cause you learn about stuff to put on the bike." He clearly stated his desire that maths should and could have personal meaning to be relevant to him.

Children who do not meet the standards imposed upon them find themselves on the fringes, where awareness of their 'weaknesses' is measured and reinforced by educational policies (Davis & Watson, 2001; James et al., 1998). From this positioning children are vulnerable to the expectations and approval of others, including their peers (Bird, 1994). At worst, it can become an encompassing vulnerability of self. Rambo's comments on learning maths highlight the need to help children to achieve the skills they value (Case-Smith, 1997), to build on their interests as ways of learning.

Achievement through work completed and rewards granted is instilled into children in primary school (Mayall, 1996). This achievement carries within it social acceptance through belonging and sameness within the culture of school (Davies, 2000). Alternatively, academic learning could be an experience of purpose through meeting the

desires for discovery and agency within children's lives. If children experience a sense of purpose within this adult constructed world of learning then the classroom can be a place of joy, self discovery and discovery of the world.

Technology and wonder. Brett, Elliot and Ian Welsh used technology in the classroom. Although this technology physically and socially separated them from their peers, highlighting their difference, their response to its use was one of joy and wonder. These boys had visual impairments and technology enabled them to see more clearly and to be more active in their learning. As they had a strong desire to learn and to achieve, technology was experienced as grace (Vardey, 1995).

Brett told me about the assessment he had undergone in Sydney for a magnifying 'glass' he used. His enthusiasm when telling me this story reminded me of Ian Welsh's joy in his discovery of computer programs and 'tricks' that would help him in school (see Chapter 8, Knowledge through experience). Elliot's recent change of schools brought new technology that enabled him to read and write independently. These boys had access to equipment that helped them to negotiate the world, to see more clearly, a wonder-filled world of technology they could use to learn.

Having a computer in class had given Brett greater agency over his learning, "And with a lot of these things now that I've got this [computer] I can join in like with the class and stuff. Back when I was in, oh well Kindergarten we didn't do much but really, Year 1 and 2 I couldn't really do much, so I had to just listen." He remained a silent observer, not being able to be actively involved. "And when I was in Year 3 I got it and, oh I started learning how to type in Year 2. I can type 44 words in a minute. So that's fun about school, I learn, and I can type." For Brett, actively creating his learning

environment had changed his experience of learning to one of joy.

These boys needed courage to take risks with their learning, creativity to problem-solve the best use of the technology, and to have trust in those helping them. Knowledge of technology became an exercise of agency. The use of technology became an avenue of transcending stereotypes of disability as powerlessness and helplessness (Davis & Watson, 2002), instead creating an awareness of the self as capable and intelligent.

Technology in the classroom may not be experienced as a social burden. Instead, it has the potential to build self-confidence through the agency of independent learning. The agency it brings may override any issues with social separation. The shared interest of peers in new technology may provide avenues to form friendships. Technology may also create experiences of being privileged compared to other students.

Negotiating Selfhood

Within their classroom experiences, children spoke of relationships with their teachers, teacher aides and peers. In these relationships they negotiated their selfhood, expressed their identities and sought to make connections of meaning. These narratives often emerged when we did feelings and qualities maps, and through our conversations on school and peer relationships.

Relations with teachers. The children's experiences of relationships with teachers narrate their consciousness of the needs and actions of others, and their pleasure in meaningful connections. These relationships were experienced as reciprocal expressions of love and belonging, or as infringements of space, privacy and ethical understandings.

Barney, Nina, Chontelle and Groovy Princess narrated times of love and belonging with teachers, times where they felt valued and supported. Barney had a close relationship with her teacher, liking her because she was a happy person and because, "I like to cuddle her up." On her happy map, Nina placed the school librarian, "I'm going to write seeing [Librarian] because I like seeing her." Chontelle's relationship with her teacher at her partner school had warmth, affection and humour, "... [she's] Really funny. She tickles [me]." Groovy Princess felt her teacher listened to children, "Yeah, yeah they listen to like, [Teacher] she listens to us." All of the children in the study related the importance of being listened to, supported, helped, believed, trusted and cared for by the important adults in their lives.

Cereberus' teacher got "cranky" with anyone that played with his wheelchair or hurt him. She was his champion and protector at school, and like him, didn't like "silly" or wrong behaviour. Even though there were school aides, his teacher and other teachers in the school helped him with toileting and sports activities. These adults were helpful with his physical needs and facilitated his engagement in meaningful activities. These teacher behaviours were also important to Elvis in his participation at school.

Children considered teachers' yelling and being insulting to be behaving badly and unjustly, transgressing the responsibility of adults in positions of authority. As Lisa told me, children ended up "Feeling unsafe in a safe place." Lisa, Nina and Groovy Princess expressed a desire for adult behaviour to be reasonable and respectful, to remain aware of the humanness of children. Teachers who did not listen to children or respect their abilities or the difficulties they experienced in learning were also considered to be behaving unjustly. Rambo's angry map contained his teacher, "She

makes me angry cause she pushes me too hard." His perception of his teacher's lack of compassion added to his dislike of school and maths (see Narratives of Learning, above).

Ineffective adult authority led to Lisa, Michael Jackson and SSS007 continuing to experience teasing and bullying from classmates. Lisa felt her teacher tried to maintain good behaviour in the classroom, "... but it doesn't work, it works, it, I listen to him but the class just still be's rude to me." In her current experience, adult authority was not impacting upon her classmates' behaviour. Her desire to be in class was being adversely affected as she continued to negotiate the bullying of others, while seeking to maintain her sense of self worth (see When people are mean, below).

In Michael Jackson's eyes, the teachers at school had not given support to him over a bullying situation, "They don't do anything. I keep telling them. I kept, two years ago I kept telling them, but they did nothing about it. I was sent to cool room cause I didn't do anything. Like, they tell you to not do it again. I got in trouble for something I didn't even do. They [the bullies] just yelled. And I didn't do anything. And then the teacher just yelled at us. I felt, actually, I wondered actually. Why, why was I sent to cool room when they did it. . . ." This was a story of teachers who chose not to hear and who meted out punishment that was undeserved. The bullying continued and he was unable to rely on the support of his teachers. He had to devise creative strategies to get away from the bullies (see When people are mean, below).

I asked Cerberus whether there were other children with disabilities at his school, "Well, me and [Sister] and just some slow walkers, like them walk slowly . . . even a teacher, one teacher, she's a religion teacher, that's her favourite sub, grade, and

like she walks slowly as well." Cerberus saw impairment only as that which was physically obvious and related to mobility, as his was. A teacher having an impairment was important to him, as it displayed acceptance and worth in being 'other' in the adult world. His comments reflect Bobby's pleasure in noticing teachers wearing glasses (see Chapter 5, An Alterity of Being). For both these boys, teachers provided role models of impairment as inclusion and importance.

Authoritarian teachers position children as powerless (Mayall, 1994; Simpson, 2000), having to accept the unethical dictates of adults. If children are not listened to or believed by adults they are vulnerable to ongoing abuse by others (James, 1993). They may also seek non-productive ways of protecting themselves and meeting their need to be heard (Moustakas, 1959).

Teachers that are reflective practitioners (Davis & Watson, 2001; Schon, 1987) enable relationships that support resilience through respect, understanding and the promotion of self-determination in children (Brown & Cohen, 1996). Teachers who are interested in the needs of the children and who seek avenues for children to be engaged in learning (Lightfoot, Mukherjee & Sloper, 2001) help children to develop identities as capable and valuable students (Turnbull & Turnbull, 2001).

A special aide. A number of the children had teacher aides or itinerant teachers to help them with their school work, sporting activities, mobility and self-care needs. Children spoke of their aides with warmth and affection, particularly if these relationships had continued over a number of years. Their relationships enabled the children's learning. Aides and special teachers were perceived as facilitators of the children's identities (Shaw, 1998) through occupational engagement.

Bobby, Max and Rambo received assistance with their schoolwork, each of them perceiving this assistance as important to their learning. Bobby told me, "Yeah I've got heaps." He had four different people over the school week. They provided assistance, "Instead of around half an hour . . . They like help me at like, they help me to read and stuff." His aides helped in activities that were meaningful for him, where he could achieve and was motivated to improve his learning skills (see Narratives of Learning, above).

Max had a "special teacher" at school, "She like helps me, with my work. . . . I always have to have a special teacher, otherwise I can't get up with work." Rather than finding the need for a special teacher onerous or creating a feeling of difference, Max was pleased he had such a teacher, "Ah yes, I actually wish I do have to have a special teacher." Like Bobby and Rambo, he recognised his need for assistance, negotiating difference through his desire to achieve.

When I asked Ian Welsh if having a visual impairment mattered to other children, he replied, "I have no idea. I think it does. Cos they think like I get all this help and everything and they go, 'Oh look at him'. Some kids. The kids in my class are like fine." The attitude of 'some kids' was related more to jealousy, where impairment became an alterity of privilege within the classroom, "I've got this lady and I normally do like computer with her on a Thursday, like, not, for like half an hour while they're doing other work. I do fun work."

None of the children spoke of their aides controlling their interactions with their peers or of contributing to a sense of otherness within the classroom. This contrasted with findings by Hemmingsson et al. (2003), Missiuna and Pollock (1991), and Skar and

Tamm (2001). For the children in this study, relationships were perceived as positive, helpful and necessary to their learning (Shaw, 1998; Shevlin et al., 2002). These relationships engendered connection with and compassion from others. Although Ian Welsh spoke of the feelings of jealousy his time with his itinerant teacher engendered in his peers, he did not perceive his relations with his classmates to be adversely affected.

Classroom dynamics. Interactions with peers within the classroom were facilitated or hindered by teaching styles and procedures. Children were also active in seeking connections or in creating space and learning away from their classmates. The dynamics of classroom interactions were a reciprocal process between children, their peers and teaching staff.

Brett and Cerberus created strategies for maintaining their learning space within the classroom. Brett desired this space so he could continue his learning without interruptions from his classmates and their requests for help. Cerberus chose to create space when children in his class were being bossy and therefore "mean", "Like, if I'm doing my own work and like they tell me what to do, like and then like I already know, like I don't care. *If you don't know, then that's ok?* Yeah, that all right. Like they're, I'm doing something and then like, them that, like, like I KNOW." He strongly objected to situations in which he was treated as if he needed help, was not as smart or as knowledgeable, his intelligence was not respected. His way of dealing with these children was to, "Just leave them. Just ignore them." He didn't retaliate; rather he removed himself from the situation. He expressed his resistance to the imposition of an identity of helpless disability (Davis & Watson, 2001).

Brett and Cerberus spoke of their awareness of their needs and the difference this

evoked in their understanding of themselves in relation to their peers. Within their narratives was a desire for belonging and respect. Knowing there were others who shared their difference contributed to a sense of sameness as a student engaged in learning.

There were other children in Brett's class at school who required help, "... he's in my class. ... Yeah, he's got trouble reading, and I don't think he can, yeah, he can't sound out the words and stuff." A second child, "He, oh well he hasn't got, the aide, but he needs like, when they do maths or something, he needs to put in, he needs the easier questions and things, so that he can learn." That these boys were in his class helped Brett to feel not so other, "It just feels a bit better for me, because like I'm not the only one doing it [needing help]. So that's better, a bit better." His comments also showed his consciousness of others, their needs and struggles.

For Bobby and Groovy Princess, feelings of otherness were engendered through physical positioning within the classroom, positioning teachers had engineered because of behaviour. Both had been moved away from other children because they talked too much. Max, Nina and Brett spoke of being placed at the front of the classroom as their teachers' response to their learning needs. However, only Nina spoke of this as an uncomfortable intrusion by the teacher on her desire for privacy and the respect of her physical space.

Children's needs for separateness and belonging in the classroom were experienced differently. In their narratives, Cerberus and Brett established their learning boundaries through maintaining their space. Bobby and Groovy Princess wished to be physically part of the class; separation brought loneliness for these children. For Bobby

it also created a very real difficulty in not being able to see the blackboard from the back of the classroom.

Children need to be supported to maintain their sense of belonging as a member of the class. However, the ways in which they wish to create and maintain their learning spaces needs to be respected. Helping children to meet their needs for interaction, participation and access to learning materials entails creative problem solving with each child. Educational practices cannot assume children's needs are homogeneous, or that practical responses can be standardised.

Friends and Bullies

Becoming friends. Speaking of school friendships and shared times in the playground brought forth narratives of how friendships were established. Within these times of connection, the children spoke of negotiating conflict, resolving differences and finding spaces of meaning with others. In these narratives, there were often spaces of loneliness as children spoke of their lack of friendships.

Michael Jackson was part of a small class at school, "Oh probably about eight or ten [children]." This was where he found his friends. Michael Jackson and his friends had been together since their early school years. The social construction of school relations had occurred around their physical belonging within the Special Education Unit. For Michael Jackson, emotional belonging was found despite society creating separateness and otherness (James, 1993).

Cerberus spoke of how he established connections with school friends, "Like my best friend's friend, and then like he become my friend, and I know his brother like, and he, them really nice." As we talked about school and his friends, Cerberus chose to draw

himself with his two friends, commenting, "I can't draw wheelchairs, so . . . I don't know how to draw them. *That's ok, so, so who's, are [Friend] or [Friend] in a wheelchair?* Nuh. *Just you?* They were just friends." His final comment implied that his friends were not connected to him through impairment but 'just' through friendship. Elvis also commented on this when we spoke of his school friends.

Rambo told me his friends didn't have impairments. He added, "They class me as the same. I don't even have sticks [crutches] when I'm around them." He and his brother go to the same school and two of their friends are brothers, "It's like we're all brothers 'cause we always hang around each other." Rambo also gained a sense of belonging and importance from being known at school, "Everybody knows me. Every single person. Even the Kindies. They've only been there for a little while. Just started. They still know me." The importance of being known supported his belief in himself as a peer of value.

Cheezel's school friendships seemed somewhat tenuous. They were children he knew rather than close or 'best' friends, "Yeah I have a lot of friends, I think I've got 11 friends. Or something. They may not be ones which are friendly . . ." But he had had a friendship that was still very important to him, "I already had a really best friend, so he, he made me feel happy to go to school because, yeah, but now, he might not, now he left school." Initially, Cheezel befriended this boy because he felt compassion for his loneliness, "But the first time I made friends with him, well usually at lunch times he's like sitting around . . . and I'm thinking to make friends with him because he looked so like he didn't have any friends." The friendship deepened outside of school and times with his friend were full of shared meaning.

Chontelle's friendship experiences included those she had made with children who had physical impairments and were experiencing isolation within mainstream schools. She spoke of two children at different schools she had attended who used wheelchairs and "had no friends", which prompted her to become friends with them. Her compassion for these children was a quality she shared with Cheezel. They were conscious of the loneliness and vulnerability experienced by other children, choosing to respond through offerings of love and belonging.

Lisa, Max and Keeta were aware of their lack of friendships. Max had few friends, "No, not much, only one friend [at school]. And one friend that doesn't go to my school." I asked Keeta if she had any friends at school she liked to play with, "I have one but she's, people call her a brat now . . . Cause she is a brat." So I asked her what kinds of games she liked playing at school, "Well I just go eat my lunch, recess." Her comments resounded with an absence of friends or others with whom to play. These children's perceptions of themselves as socially valuable were threatened, making them vulnerable through loneliness (James, 1993; Moustakas, 1961). If their experiences of loneliness persist over time, then their perceptions could become those of self-worthlessness (Bronfenbrenner, 1995; Kirova-Petrova, 2000).

Many of the children in this study had limited friendships. Their opportunities to develop friendships were restricted by their ability or desire to participate in playground games (see Shared meaning, below). They were also isolated because of perceptions of their identities as 'disabled' (Hurley-Geffner, 1995; Reeve, 2002). Other children treated them as different and did not want to make friends with them. The friendships they did have were very important to them, being placed on children's trust and happy maps.

These friendships offered love and belonging, and enabled children to express their identities without a focus on their impairment.

Being a friend. Asking the children about the qualities they would like in a 'best friend' and the qualities they liked in a friend, brought forth narratives of current friendships and desires for different relationships. Narratives of friendship qualities emerged when children talked of the qualities of 'good' and 'bad' people. The most frequently spoken of embodied qualities desired in a friend were helping, kindness, sharing and support. These related to the spiritual qualities of love and compassion sought in others, and grace received from another. Woven within the narratives of friendship were the children's courage in asking for and trusting others to help them.

Receiving help from friends was important to Brett, Elvis, Chontelle and Ian Welsh. Brett's school friends, "Well they're helpful with me. Well [Friend] and [Friend], they always, cause I'm colour blind . . . they always help me with the colours and, tell me what's what, and stuff. They help me when I forget my binoculars or something, what's on the board and stuff. So that really helps a lot." His friends helped him to 'see' his world and continue his learning at school.

Elvis valued friendship qualities of kindness and helping him to do physical things, "Like he [Best Friend] helps me with stuff . . . moving around stuff." Elvis' friends were ". . . not question askers." He appeared to consider this a very positive trait. Friends were those who were not intrusive, did not bring attention to his physical difference and respected his right to privacy. His feelings reflected those of Elliot, who spoke of the intrusion into the privacy of his impairment he had experienced at his previous school. Elliot valued honesty, respect and empathy. These embodied qualities

of love and compassion were positive for him to give and receive. Elliot, like many of the children, appreciated friends who helped him to engage in activities he enjoyed, such as reading to him at lunchtime.

Lisa and Bobby spoke of friends embodied in an otherness of self. Lisa's desires in a 'perfect best friend' were told through a story of a girl who was almost a cousin, with the same interests, likes and dislikes. This imagined girl would be in her life until they were very old and would give Lisa her dream of a horse (see Chapter 6, Rhythms & Rituals). Her friend was in some ways lesser, a little younger, with hair a little less blond, perhaps a friend she could be better than (see Appendix R, p. 353). Bobby's idea of a perfect best friend was, "... a dog." Their desire for friendships other than those they currently experienced, tells of their desire for more meaningful connections with other children.

Within the children's narratives of friendship, there was a commonality of desire for love and compassion. The best friends to have were those who offered practical and emotional support without overtones of pity. All of the children in the study wanted their impairment to be socially irrelevant to others. Children offered their friends the qualities they sought (Giddens, 1991; Staub, 1998). They were compassionate, loving, and ethical towards their friends. The bonds of friendship evoked other spiritual qualities, such as joy, trust, courage and grace.

Shared meaning. Sharing moments of meaning with friends was important to all of the children. These moments were often within the school playground. They could be unstructured times of being together without having to achieve any goal, where creativity could become enfolded with belonging. Cultural games of childhood were

enacted that gave structure to being together. The sharing of roles, trying out of identities and rules could be woven with the pleasure of competition and excitement (Reilly, 1974; Winnicott, 1971). Restrictions in playing with friends occurred through differences in interests, and, for Elvis and Cerberus, through their physical restrictions.

Deatherford, Lisa and SSS007 spent time in imaginative play with their friends. Two of Deatherford's friends were in his class at school. On the playground they met with other friends, spending time being together without precise plans, "Usually just playing, we don't have, we just play stuff usually . . . we just play anything really. Anything that we can think about." These times with friends offered freedom from rules and decisions. He and his friends were able to be creative and open to the moment (Csikzentimihalyi, 1990).

Like Elvis, Lisa's favourite part of school was, "The part about recess and lunch is playing, that's my favourite part, play time." Lisa and her friends used these times to create games and "play silly stuff". For these children, the freedom from adult temporal and spatial rules was important to their play experiences (Bundy, 2003; Reilly, 1974; Singer, 1973).

Ian Welsh, Chontelle and Barney enjoyed physical games with their friends. For Ian Welsh, games at school gave times of connection and shared meaning with friends, "Ah, well at little lunch we play, tips, before school we normally play just build-ups, or bull-rush." These times gave a space where he and his peers were free from adult direction. They created their own rules and boundaries within cultural games of childhood.

Bobby, Nina and Cheezel spoke of not joining their friends in activities because

their interests differed. At school recess times, Bobby and his friends, "When it's raining we play like checkers or cards. Checkers or cards, yeah. Or something like that. Or computer . . ." However, if the weather was fine and they were outside, "I don't play with my friends. They play WWF, they play wrestling so I watch it. I don't want to get hit . . . and I don't want to get in trouble." Children were not allowed to wrestle at school, "But they still do it." At school play times, Nina's friend, ". . . goes and chases boys. And I just go somewhere else and play with someone else, cause I don't want to chase the boys." In the second half of lunchtime, Cheezel went to the library where, ". . . I want to play chess." These children chose not to participate and created alternatives to their friends' games. They were agentic in choosing to engage in activities that had meaning for them despite the temporary disconnection from their friends.

SSS007 and his best friend 'spied' on others and had creatively incorporated exercises to strengthen his arm and leg. In contrast, Cerberus and Elvis were unable to share in the games friends enjoyed at recess because of their physical restrictions. I asked Cerberus whether there were children at school he could talk with about his interests in animals and myths, "I don't know them all, I mostly the only friends I . . . well my friends . . . that I got, them normally don't think about hard game what I can play, and one I can't even play like soccer." His narrative spoke of aloneness and disconnection through his friends' not accommodating his desire to play (Tamm & Skar, 2000). He was made conscious of his body and its corporality (Bleeker & Mulderij, 1992; Merleau-Ponty, 1962). There were other children who were happy to talk with him. These children 'understood' his inability to play physically active games and his desire for other activities, "Sometimes, well the older kids, like Year 3 and 4, and all

those kind of kids, they're all really nice, them understand like."

Playtime was Elvis' favourite time at school "Cos you can eat food and talk to your friends and stuff like that." Even though both these boys wished they could participate in their friends' games they had created other ways of being with peers. Through these avenues they were continuing to develop their social skills and maintaining a sense of belonging within their peer culture. They did remain vulnerable to isolation from their friends. They were also vulnerable to development of their peer identity as 'disabled' and unwanted within physical play (Missiuna & Pollock, 1991; Tamm & Skar, 2000).

The children's narratives highlight their unique interests in shared play and leisure. Having friends who shared their interests led to joy and creativity. Children who had different interests to their friends were active in seeking other children with whom to interact. Their stories spoke of their ability to meet their needs, expressing their identities through moments of play and leisure. Those children unable to participate physically in play sought other ways of being with peers. However, their narratives also spoke of the consequent social barriers to the deepening of their friendships.

If teachers, therapists and parents wish children to engage in play and leisure experiences at school, children's desires must be respected. They cannot assume all children wish to engage in physical play, nor that they always wish to play the games of their friends. To enable children to experience belonging, joy and creativity within play and leisure there needs to be an understanding of how they already seek to do so. Respecting children's abilities to meet their needs means adults can co-construct strategies to enable them to be with friends and other peers who share their interests.

Doing so will reinforce to children their ability to care for themselves, that they are agentic. Inclusive play spaces need to enable children to create their own spaces by encouraging interaction and diversity.

Negotiating disconnection. All of the children, except Brett, had said they did not fight with their friends. However, they did experience times of disconnection. Their narratives spoke of times where they faced isolation and jealousy, where trust and faith in another was fractured. During these difficult times they needed to continue believing in themselves and their uniqueness. These times of disconnection were often spoken of in our conversations on angry and sad feelings.

Groovy Princess had established friendships at her current school, but these friendships were not easy for her to negotiate. A friend who featured in many of Groovy Princess' narratives emotionally pushed her away. Groovy Princess thought this friend was sometimes nice and sometimes, "A bit of a mean person." This friendship was fraught with the uncertainty, constant renegotiation and repositioning that can occur within a larger group of girls (James, 1993; Lamb, 2001). The potential loss of friendship was also an issue for Bobby. While we were doing his angry map, he told me, "If I have no friends, I get mad." This feeling happened when, "If I get bad they say, 'Oh I'm not his friend' I get mad." His comments seemed to be borne from sadness as well as anger at being rejected because of his behaviour.

Lisa chose to do a feeling map for jealous. This feeling was significant for her as she experienced it in her relationship with her good friend, "Well my friend and my, I mean, my friend plays with me and we have a shared area where we meet. My sister and my sister's friend and those two always play with [Good Friend] and [Another Friend]

and so . . . and they always jump around with [Good Friend] and they say [Good Friend] my favourite one and that makes me really jealous and I try and get their attention. And they think she's the best too. So I get really jealous and I try and make them pay attention to me and stuff."

She was conscious of her feelings and how she tried to make herself be seen by the other children, "Yeah I don't really normally get jealous, I only get jealous when [Good Friend] around me." Her feelings of being lesser perhaps tie in with her desire for an ideal best friend placed somewhat lesser than herself (see Being a friend, above). Lisa's desire to belong and to be seen as a friend of value struggled with her feelings of jealousy.

Elvis and I spoke at length about the issue of a school friend refusing to give him his home phone number. This issue was an example he gave of his feelings of sadness in response to someone being 'mean', "A real mean person. Even that bit when he called me a stranger . . . but I'm not a stranger, I'm a friend"! The other child denied the presence of friendship, of Elvis having value in his life, positioning him as other.

This experience had shaken his sense of safety in the world of friendship, leaving him with a precarious sense of belonging. However, this was preferable to isolation and continued meanness. Feelings of frustration and sadness were all too real, "It's about friends, not about being mean to each other. Not letting me have the opportunity to be friends, you see? And friends should give opportunities to do that." Friends should give openings for another's friendship, opportunities for connection and shared meaning.

For Elvis, the phone number issue foregrounded the meaning of trust within this friendship. He found a way to contain the damage to the friendship, "I would still be his

friend but I won't talk about the phone number bit anyway, anymore, that's all about the trust . . . But I would still trust him [about everything else]". But his reasons for doing so were based on his fear of possible reprisal, "I couldn't really do anything else. There's nothing I could do, like couldn't do like not be friends anymore cause then he would still be like, still be even meaner to me, right? And that's the hard part." Continued trust in his friend was not based on the other's inherent goodness or expressions of trustworthiness, but on Elvis' need for emotional safety and survival. He needed to sustain the connection with this friend despite the cost to his sense of ethics. His vulnerability in the face of potential loss caused him to sublimate his identity.

Sustaining the friendship provided an affirmation of life but created an underground current of anger, enacted within his stories of hope and joy (see Chapter 5, *Being Themselves*) being experienced through destruction (Moustakas, 1961). Elvis saw himself as a child who needed help to survive (see Chapter 5, *An Alterity of Being*). For him, his very existence depended on the kindness of others. The loss of a friendship was a very serious matter, being not only an emotional loss but also a threat to his physical survival.

Negotiating friendship difficulties was experienced by all of the children in this study as a part of school life, as it is for many other children (James, 1993; Staub, 1998). The meanings within the children's actions when dealing with others, speak of the importance of friendships within their lives. Friendships were maintained despite emotional challenges. The children's ability to negotiate these difficulties tells us of their resilience to ongoing threats to their sense of self. Their responses also tell us of their vulnerability to the actions of others and the emotional price they pay to sustain

connections.

When people are mean. Many of the children experienced bullying from their peers due to their impairment or in response to their personality. Children spoke of their right not to be bullied. They had developed different coping strategies; moving away from others, telling teachers, and fighting back. These narratives arose when we spoke of children at school they did not like, and when doing feeling and qualities maps.

Lisa experienced a lack of connection with her peers. She didn't like, "The people in my class. *Yeah? All of them?* [she nodded] *Yeah! How come?* They're mean to me." They didn't call her names, ". . . they just, they're just mean, rude. There's this real mean girl, she thinks I ignore her but I don't and cause she just does complaints and she's snobby, she, yesterday she, she growled at me, well she yelled at me, yeah. I hate her. Like everyone in my class likes each other but except I hate everybody. Like everybody in my class likes each other except for me and I don't like them, so, yeah." She felt excluded and disliked, which she returned, perhaps as a strategy to resist their positioning of her.

Talking about these issues made Lisa teary-eyed. These classroom moments were difficult for her to endure. She was made other when she wanted to be accepted, feeling very alone and unwanted. Lisa's experiences with her classmates featured in her courage map, "[Lisa] at school, is, gets teased by kids but, is brave." She drew on her courage everyday and continued to find joy in learning in a hostile classroom environment. Her resilience of spirit enabled her to continue to attend school.

Although Chontelle considered her partner school, "A good school", she still had to negotiate relationships with children who did not understand or respect her. When

discussing a child who was 'mean', she spoke of a girl in her class, "... she sits with the teacher." Her comment indicated this girl's behaviour had come under the discipline of adult authority (Foucault, 1977). This girl was also mean to other children, "... she's mean to [a child who had a cochlear implant] or the other kids like [a child who wore hearing aids]..." This girl perceived children with disabilities as lesser and chose to victimise them because of their difference (Rigby, 2002).

The sadness and anger Elliot experienced over bullying was expressed in these statements, "I just feel angry if I get bullied and people get bullied. Just, it's not right! I just feel like, if I had a megaphone I just feel like, I'm in space and I shout to the whole world, 'Bullying is wrong, bullying is wrong'. I just feel like running off into my own, I just feel like running off and crying somewhere. And it makes me want to just tear the place apart. I just feel like beating someone up and crying at the same time. It's not right." Elliot's sadness and anger were responses common to the children who narrated experiences of bullying (Rigby, 2002).

Michael Jackson spoke of trusting his friends, "Except some of them. Some of them I don't trust, but they're not my friends anyway. They used to be." These ex-friends had bullied him, "They kept chasing me around the school playgrounds ... they were trying to bash me up. It's kind of like a bully thing. They used to do that to me. I don't know why they were doing it, they just did it." These bullies were three other children from the Special Education Unit who also used wheelchairs.

Before Michael Jackson's sister went on to high school she used to protect him from these bullies, "My sister had to keep telling them to stop. She was defending me. And now she's not around any more, [but] they don't tease me as much. I can get away

from them easily now. Cause I didn't know how to go fast like that, at that age." He had learnt how to use his body and his wheelchair in a way that made him move faster than the bullies. Chontelle had a friend at school who intervened when other children teased her, "They're, they're, they, they tell, [Friend] tell them not to bother me." Like Michael Jackson, the support and protection of others was important.

Chontelle's advice on how to deal with children who were mean was to, "Ignore them." She asserted her resistance through non-response, a strategy she shared with Cerberus and Deatherford. She chose not to retaliate in a like way. Through this strategy she met her ethical needs as well as remaining within the bounds of the school's code of behaviour. Chontelle's strategy reflected her position on fighting with her sister (see Chapter 6, Rules of engagement) where she felt it was wrong to hit back.

Elliot, like many of the other children, chose to be alone while he worked through his feelings and regained his emotional balance, "I just have a cry and like say how angry I am. And just, and then just shake it off. But I usually speak to myself in the toilets and stuff, just in a private place, and I just cry and talk about how angry and like annoying and stupid they are. And then I just shake it off and say, I just shake it off and say 'Well they don't know me. Like they're really annoying but I'll stay away from them'. And I do." He regained his sense of self by positioning bullies as ignorant of his self-worth. He had told me that in the past he used to fight back. He had decided non-violence reflected his ethical sense and desired way of being in the world.

Rambo and his friends created their own justice, "... if people tease us then they get bashed. They call me four legs, so I bust the crap out of them. I broke a kid's nose because of that." Rambo also defended his brother, "People at school, he pinches

people and they get really angry. That's why they used to bash him so he bashed them back. They call him fattie [which is why his brother pinched them]. So I bash 'em." In contrast to Chontelle and Elliot, he had chosen not to quietly walk away. He actively resisted the negative stereotyping of himself and his brother (Davis & Watson, 2002).

His experience of teachers was, "Oh they don't do anything. So you just sort it out yourself. I never do [tell the teacher]. Teachers are hopeless. Yeah, they don't do anything. They just say, 'Say sorry', and that's not good enough [because it happens again]. They [bullies] should get put on a level [disciplinary procedure] or something." His comments on the ineffectiveness of teacher intervention were echoed in the narratives of Groovy Princess, SSS007 and Michael Jackson. Vulnerability through a lack of adult support forced children to become resourceful, in positive and negative ways, in defending their right to be (James, 1993).

Children spoke of how they were no longer able to trust peers who had bullied them, rather they had to remain vigilant. This vigilance was not their preferred way of being, which saddened them. Elliot, Michael Jackson and SSS007 spoke about forgiveness and trust. Their narratives spoke of a resilience of spirit, within which they sustained their belief in themselves and their ethical codes of behaviour.

Elliot reflected on forgiveness, "Well it's a pretty hard job because forgiving someone for what they did to you is very hard, because all the grief you suffered is caused by them, and usually sometimes you think they don't deserve to be forgiven. But they actually do. Because like, they need a second chance, and even if like you never forgive them, then they will always feel guilty. But like forgiving is like a second chance, and even if they annoy you just go tell the teacher. And you just forgive them

for what they did." His forgiveness was borne of compassion. But his compassion was not naive because the hurt inflicted by another changed the way he trusted, "Yeah. Because like you're, you're aware now that they might do something to you. So you only trust them in little things. Cause they might like [do it again]." Like the experiences of Elvis with his friend (see Negotiating disconnection, above) and Lisa with her siblings (see Chapter 6, Being trusted), it became a considered trust.

Michael Jackson had forgiven one of the bullies, "But someone, no, but one of them's my friend again. Only just one of them is. The others I don't quite trust yet. And we're pretty good friends now so." The change from not being a friend to becoming a friend once more involved an offering of apology and friendship from the other child, "Cause I never started to talk to him after that. Yeah he started talking to me, being my friend and talking to me, cause he had no-one to talk to. He said 'Sorry' and I said 'Yeah, yeah'. And then we started getting things back the way they were." Michael Jackson empathised with the boy's loneliness of having no-one to talk to. He felt this boy would have been "Very lonely." He had the generosity of spirit to forgive.

The ability of these boys to forgive others speaks of their wisdom and compassion. These qualities strengthened their resilience through healing the emotional wounds of abuse. Although they still felt vulnerable, they were able to continue to engage in peer relations. Their resilience of spirit enabled them to negotiate the uncertainty of the playground on a daily basis.

SSS007 tried to forgive his tormentor, but found it very difficult. I asked him how 'you' forgave a bully, he replied honestly and with concern, "I can't. I wish I could but I can't." His feelings of injustice and hurt ran too deeply within him. The situation

was made more difficult because this boy was in his class, he couldn't ignore him, "No. I can't. He's too mean." He was in a situation from which he could not walk away or resolve, continuing to be bullied in class and in the playground.

The children's experiences of bullying and isolation reflect the stories of hero journeys many liked to read (Campbell, 1949) (see Chapter 5, Part of the story). Their narratives were filled with courage and resilience. They experienced daily journeys of confronting 'trials, monsters and defeat' but kept on going to school, retaining hope and belief in themselves. Resilience was understood and experienced in different ways by each child. However, they shared a common faith and trust in, and love for, the self.

The positioning of these children by their peers reflected society's positioning of them. Peers internalised and acted out this positioning (Davis & Watson, 2001; Reeve, 2002; Rigby, 2002). The children chose different ways of resisting otherness (Davis & Watson, 2002; Shaw, 1998), protecting their physical and emotional self. Although friends and teachers could be protectors and allies (Brannen et al., 2000; Prellwitz & Tamm, 2000), this was not the situation for all of the children.

The children in the above narratives needed to draw on the spiritual qualities of courage, faith and ethics to meet the difficulty of being bullied, often on a daily basis. Through their experiences, they formed an embodied ethic for living in the world. In contrast to concerns highlighted in the literature (Rigby, 2002), none of the children in this study spoke of avoiding going to school. They all demonstrated a resilience of spirit through their ability to continue going to school despite the abuse they experienced. Courage was embodied in their reflective understanding of these daily negotiations while continuing to seek and experience pleasure within other aspects of school life.

Implications for Practice

For while childhood may be a biological fact, the way in which it is understood and lived is socially determined, within an actively negotiated set of social relations . . .

(Moss & Petrie, 2002, p. 20)

The positioning of children with disabilities within the education system tells them they are valued differently to their peers in terms of their school identity (Owen & Tarr, 1998; Shaw, 1998). Children's lived experiences of policy may shape their student identity as one of being other. Children's lives and identities are shaped by the effects of policy discourses and institutional practices operating through implicit norms, underpinned by normal/abnormal, able/disabled dualisms. As occupational therapists working within school systems, we need to remain aware of the impact of educational policies on children's understandings of themselves as part of the school culture.

The positioning of children at macro levels (Bronfenbrenner, 1979) inevitably constructs their micro everyday experience, including the perceptions and responses of teachers and peers. We must be active in promoting inclusiveness (Townsend, 1997, 2003). If we wish to enable children to develop a resilient sense of self, then we must involve ourselves in advocating for their inclusion at all levels of school policy construction (Fattore & Turnbull, 2000; Law & Dunn, 1993; Turnbull & Turnbull, 2001). School is much more than a functional space. As a highly governed and regulated space, it has different effects on children's experiences of self. Even in 'inclusive' environments, inclusion is still premised on difference from normality, rather than difference that reflects diversity.

Like the developmental milestones on which they are based, educational 'milestones' can mark children with an identity of success or failure. Our role in

assisting children with learning difficulties must encompass the minimisation of negative social positioning by teachers and peers (Davis & Watson, 2001). To promote their resilience to external markers of performance, we need to build on children's intrinsic interests that in turn lead to a sense of worth as capable learners.

Like teachers, we need to be reflective practitioners (Schon, 1987) if we are to foster children's resilience. This means building supportive relationships with children (Case-Smith, 1997) based on trust and respect (Hinojosa & Kramer, 1999a). Through sharing these qualities with children, we enable them to build these qualities into their relationships with us and others. We need to respect children as capable of creative problem solving and ask them to share their strategies with us. When working with teachers, we can help them to reframe children's behaviours (Case-Smith; Pollock & Stewart, 1998; Richardson, 2002), fostering perceptions of children as agentic and ethical. In this way, we can advocate for children within the classroom, suggesting alternate methods to enable positive relationships in which children can be seen and heard.

Aides and itinerant teachers can enable children to maintain and build their student identities as learners and achievers. When working with support personnel, we need to be aware of the possible meaning of the relationship for children (Hemmingsson et al., 2003; Shaw, 1998; Skar & Tamm, 2001). If mutual power is enacted within the relationship, it can build the resilience of children within learning experiences. When providing occupational therapy services, it may be beneficial to use this established relationship to engage children in challenging tasks within a known space of trust. The importance of continuity, mutual liking and respect asks us to advocate for children to

maintain relationships with preferred support staff over their primary years.

If children are to experience resilience through connection (Hunter, 2001), then we also need to enable them to participate in activities that promote the development of friendships (Missiuna & Pollock, 1991; Richardson, 2002; Staub, 1998). Friendship building activities will engender a sense of belonging with others (James, 1993), and hope and faith in the self. The development of children's social skills will enable them to gain confidence in approaching and being with other children (Hurley-Geffner, 1995; Staub). Being perceived by other children as a valuable member of the group will help children to build an alternate social perception of disability, as one of difference defined in a positive relation with normality.

If we wish to support children's resilience within friendships we need to enable them to develop ways of negotiating disconnection, minimising the threat to their sense of self. Helping children to define their emotional boundaries will help to sustain their identities. Helping them to develop the skills they need to deal with friendship conflicts will also help them to negotiate bullying and isolation experienced within other peer relationships.

We can play a vital role in helping children to cope with the challenges of negative stereotyping. We can build children's resilience by enabling them to build their self-esteem. Helping children to be aware of the spiritual qualities they have, and how they already embody them in their everyday lives, can reinforce in them that they have internal resources on which they can rely. Discussing strategies with them to care for themselves emotionally and physically will position them as agentic in meeting their needs. At the microsystem level (Bronfenbrenner, 1979), we need to engage with

teachers and children in determining strategies for children's safety. We also need to be proactive in collaborating on strategies that alter peer perceptions of children with disabilities to those of worth and agency (Davis & Watson, 2001; Hurley-Geffner, 1995).

Play (and leisure) occurs in social contexts (James et al., 1998; Greene, 1997). When we evaluate children's occupational performance skills (Canadian Association of Occupational Therapists, 1996), we must consider the complexities of social interaction. Shared play and leisure at school impacts upon children's identities through the interpersonal skills they learn and offer (Missiuna & Pollock, 1991; Staub, 1998). We can enable them to build their resilience through pleasurable engagement with their peers (Hunter, 2001). Resilience will form through the creative use of resourcefulness, adaptability and flexibility (Sheldrake, 1989), and will develop through the spiritual qualities of love, belonging, trust, purpose and joy embodied in moments of shared meaning.

Children seek to be valued, to be active and creative agents of their learning within the classroom and the playground (Davis & Watson, 2002). How they seek and experience belonging with their teachers and peers tells us of their need to be seen as unique and the same (Ricoeur, 1992). We need to participate with children in creating resilient school environments in which there is adult support, engagement in learning, reciprocal friendships, and participation with peers. In short, we should seek full inclusion where all children are valued and respected.

Chapter 8: The Wider World

All children and their families need to feel like they belong, and [a] "sense of belonging" is enhanced through time spent engaged in activities in their communities.

(Mulligan, 2003, p. 118)

Children's life contexts include the community (Bronfenbrenner, 1979; Mulligan, 2003) and beyond. Within occupational therapy research there has been a limited focus on community involvement for children with disabilities (King et al., 2003). Occupational therapy interest in community involvement appears to be cursory, often being situated within school contexts (e.g., Pollock & Stewart, 1998). Literature in sociology also focuses largely on home and school (James et al., 1998; Mayall, 1994) discussing children's experiences within communities from the broader viewpoints of political impacts and social structures.

Grady (1996) and Townsend (1997) discussed the importance of community inclusiveness. This inclusiveness must embrace *children's* lives within community spaces. The children in this study spoke of being within community contexts of sport and leisure, medical and support services, and religious faith activities. They also spoke of their consciousness of issues affecting the world, and their compassion for others.

The importance of community leisure for children with disabilities has received limited attention in occupational therapy literature (King et al., 2003; Law et al., 1999) or in disability and leisure research (Aitchison, 2003). Children's participation in neighbourhood life, sport and recreation provides opportunities for the development of friendships and skills (Jones, 2003/2004; King et al.; Specht, King, Brown & Foris, 2002). Friendships can in turn foster children's participation. Through leisure, children can explore their identities outside the boundaries of roles constructed within family and

school contexts. They can engage in activities that challenge physical, sensory and cognitive boundaries, thereby challenging their perceptions of themselves and the perceptions of others (Specht et al.). Leisure is also importantly a domain of 'relative freedom' that is even more important for children whose lives are surveilled by adults (Aitchison).

For children with disabilities, the community context of medical and disability services is a significant and ongoing part of their lives. Occupational therapy research in this context has been quantitative, focusing on the measurement of intervention practices (e.g., Chen, Heinemann, Bode, Granger & Mallinson, 2004). There has been little interest in children's experiences and their influences on identity. The sociological research by Alderson (1993) and photographic essays by Krementz (1989, 1992) present children's knowledge of, and insight into, their medical and health needs. As occupational therapists, it is important to further our understanding of how therapeutic relationships and practices impact upon children's sense of self.

Many children participate in religious faith practices as part of their family life. Their participation involves them in a religious faith community. This community also brings a sense of belonging. The work of Hart (2003) and Coles (1990) highlights the importance of religious faith in the lives of children. The work of Simo-Algado, Mehta, Kronenberg, Cockburn and Kirsch (2002) asks us not to neglect the significance of religious faith in supporting children's resilience.

Occupational therapy literature does not consider children's world consciousness. We do not have an understanding of the ways in which children consider the world and the issues of which they are aware. Coles' (1986, 1989) interviews with

children in a variety of life circumstances highlighted children's awareness of the issues affecting their world and the worlds of others, reflecting their ethical understandings and the ways in which global issues affect their lives.

This chapter explores children's narratives of their involvement in the wider world. Their perceptions embraced the physical and cultural dimensions of their world. They saw the world as neglectful, puzzling, demanding, joyful and enriching to their identities and spirituality. Their engagement in community contexts was formed from their desire to be with others, with nature and within their religious faith, to be part of the world.

Leisure

The children identified leisure experiences when we talked about what they liked to do. Narratives of leisure were also raised through their feelings and qualities maps, as well as in conversations about family and friends. Participating in leisure activities outside of school, with family (see Chapter 6, Rhythms & Rituals) or friends, enabled engagement with the wider world. These activities evoked belonging, transcendence, hope and courage, and connected with activities they enjoyed at home and at school, creating an intertwining of purpose and joy across these contexts. Children's participation brought a sense of belonging within their community. Restrictions were felt in relation to environmental barriers, the attitudes of adults and other children, and 'rules'. As with school, children had to negotiate exclusionary attitudes in their relations with others.

Neighbourhood friends. When we talked of school, the children sometimes spoke of neighbourhood friendships. Brett and Rambo easily traversed school and

neighbourhood friendships, unique experiences compared to the other children. Most of the children in this study had limited friendships within their neighbourhoods. Max, Ian Welsh, Chontelle, Nina and Deatherford spoke of neighbourhood friends. The other children did not speak of any friendships within this context.

Brett lived in a small rural town. His friends were, "About nine of them out of sixteen [in his class]." When not at school, "Oh we sometimes go around [bike] riding, just round the streets." Times away from school and home enabled freedom, where the only purpose was being together. Rambo and his friends often visited each other. For these two boys, friendships could be maintained and deepened across contexts.

I asked Max whether he thought children were brave. My question sparked a lengthy story of boys and their deeds when no adults were around to caution or hinder, "Kids? Yeah. Boys are, like they always like doing cool stuff like bungy jumping. I do rock climbing. Or usually go on exploring trips through the bushes, without even an, without a companing [accompanying] adult. Yeah, just like playing in a park . . . and we had our own tree, a special tree house, make a tree house . . . then we wreck it when we're going home, so others can't find it. Or if anyone wants to come up we jump down and chase them away on our bikes. . . . Cause we made a club. We went on a trip to through bush at the park, there was this whole bunch of mud fields. . . . We mainly went, jumped across rocks. Which is hard. No adult could have done it cause they would have fallen in cause the rocks would have sank deeper in the mud." Max experienced being part of a group, a 'club', through his brother's connections with other children. Although Max's narrative was not a 'quest', it was a story of power, agency, adventure, daring and danger, of courage lived in the moment and shared with other boys.

Chontelle and Nina each had a school friend who was also their neighbourhood friend. In her neighbourhood, Chontelle said, "But I go over to [Friend]'s place, all the time. [Friend] lives up the road." She had someone to visit and play with but she was aware of her lack of neighbourhood friends, "One person." There was a sense of isolation from life within her neighbourhood. Other neighbourhood children formed groups and she spoke of being excluded and bullied. She had to negotiate difficult peer relations at school (see Chapter 7, When people are mean) and in her neighbourhood.

Nina saw her friend every Friday after school and they sometimes went swimming together. School friends were part of other children's community circles. Michael Jackson spoke of seeing school friends when he went to respite care. Elvis saw school friends at Sunday School. All of the children who were able to spend leisure time with either neighbourhood friends or school friends found spaces of belonging. These times enabled the deepening of emotional bonds (Staub, 1998) through the sharing of joy and creativity.

When I asked Keeta what else made her happy, suggesting playing with friends, she replied, "Playing with Imelda." I tried to pursue whether she had any friends she liked to play with. She initially avoided the question by changing the subject. She then told me, "[Friend]. Well she's actually, I've been her friend for a long time and some people say if you've been a very long time, I've been friends with her since she was two or three and now she's five or six. And they say you've been, you've become cousins . . . because you've been their friend for a long time. So you'll be my cousin for a little while. . . . She's, when I go with dad I play with her, but now dad and her mum have broke up."

This had been an important friendship for Keeta but changes in adult relations had meant an ending not of her choice. Like the children who had lost or were losing friendships through school changes (see Chapter 7, Changing Spaces) her emotional need to maintain the friendship had been overridden by adult decisions. Her poignant inclusion of me as a 'cousin' spoke of her desire for closeness with another with whom to play, and a sense of loss and loneliness with that realisation (Moustakas, 1961).

Many of the children lived in urban areas (Appendix M) where the accessibility and safety of traversing and playing in neighbourhood spaces was limited (Gleeson, 1999; James et al., 1998). The sense of loneliness evident in most children's narratives of neighbourhood friendships reflected their sense of isolation at school (see Chapter 7, Friends & Bullies). They were in contexts where peer relationships could potentially be formed but they were either excluded, like Chontelle, or did not have opportunities that fostered friendships.

Part of the team. Many of the children were involved in organised sport, from swimming to rugby. Their participation enabled purpose, belonging and joy as part of a team. The children spoke of their sport while we did happy maps, talked of what they would like to change in their lives, discussed friendships and their favourite things to do.

For Ian Welsh, purpose and passion were found in competition swimming and basketball. He had been involved in swimming for a number of years, "... because I've been doing swimming for five or seven years." There was continuity, dedication and discipline, "I do it [swimming training] like twice a week. I do all of them [swimming styles]. Medley, butterfly, I didn't care what I did. Even if it was 1500 [metres], I'd do

that." He participated in swim meets, recently winning a gold medal. His ongoing passion for swimming was intertwined with his desire to compete as an adult (see Chapter 5, Becoming).

Ian Welsh's friends at school and those with whom he played competition basketball were important to him. He used to play soccer but his visual impairment made it too difficult, "It was just too glarey with the sun." There were limitations on how long he could play for and when he could play, "Like I only ever play, I don't know, a little section, otherwise I play at night." His restricted participation gave an experience of otherness within the team. However, loss became gain when he quit soccer and began playing basketball. He said philosophically, "Ahh, well I wanted to quit. Yeah it was fine. Like I was getting along [better] with my new friends now than when I did with my soccer team. Because I see them all every day and we play a game of basketball every single day." Playing basketball (without the limitations previously imposed by his visual impairment) enabled daily times of shared purpose and belonging.

Brett's future desire to play professional football was quashed by his need to wear glasses, "Well I've been wanting to play football, and [Brother] was supposed to play football, and then [Another Brother] started playing this year, but yeah, that's when I really, really wanted to play, and dad just told me I couldn't, so." The restriction seemed to bite deeply, "*Is that the first time your eyes have sort of stopped you, doing something you really want?* No. I wasn't allowed to play football for the school, yeah. Wasn't allowed to, I wasn't allowed to do much at all really." Although he had been 'not allowed to' before, this time it mattered more to him. He was excluded from participating in the world of competition football with his brothers.

Like Ian Welsh, Brett had found alternatives. He had been playing soccer for a number of years, "I've been playing indoor for about . . . two and a half years and outdoor for eight years." He had a sport that met his desire for action, mastery and being part of a team. In another conversation I asked him about his personal qualities, "I suppose skill to run. And I made it to, District [level of competition]. I wish, yeah, you've got to have, got to have speed, cause . . . it's a gift, I suppose." He embraced this 'gift', competing at higher levels and winning.

Max played rugby at school, and outside of school played basketball, soccer, tennis, went to Tae Kwon Do and Scouts. However, all of these activities did not appear to have created opportunities for further friendships, even though, "Yeah the, everything I do I've got different kids. . . . I like all of them." Perhaps the lack of continuity of contact hindered deeper connections. Max spoke of a boy who had been his best friend, "Maybe, I don't think you know this guy, I play basketball with him . . . but if there was something like being my best friend for five years. Or three or five years . . . we're just really good friends. Except we can't meet each other for like five weeks in a row, haven't met him like all this year, all this year." This absent friendship remained through the shared meaning of basketball. Opportunities to see his friend were governed by the basketball competition schedule.

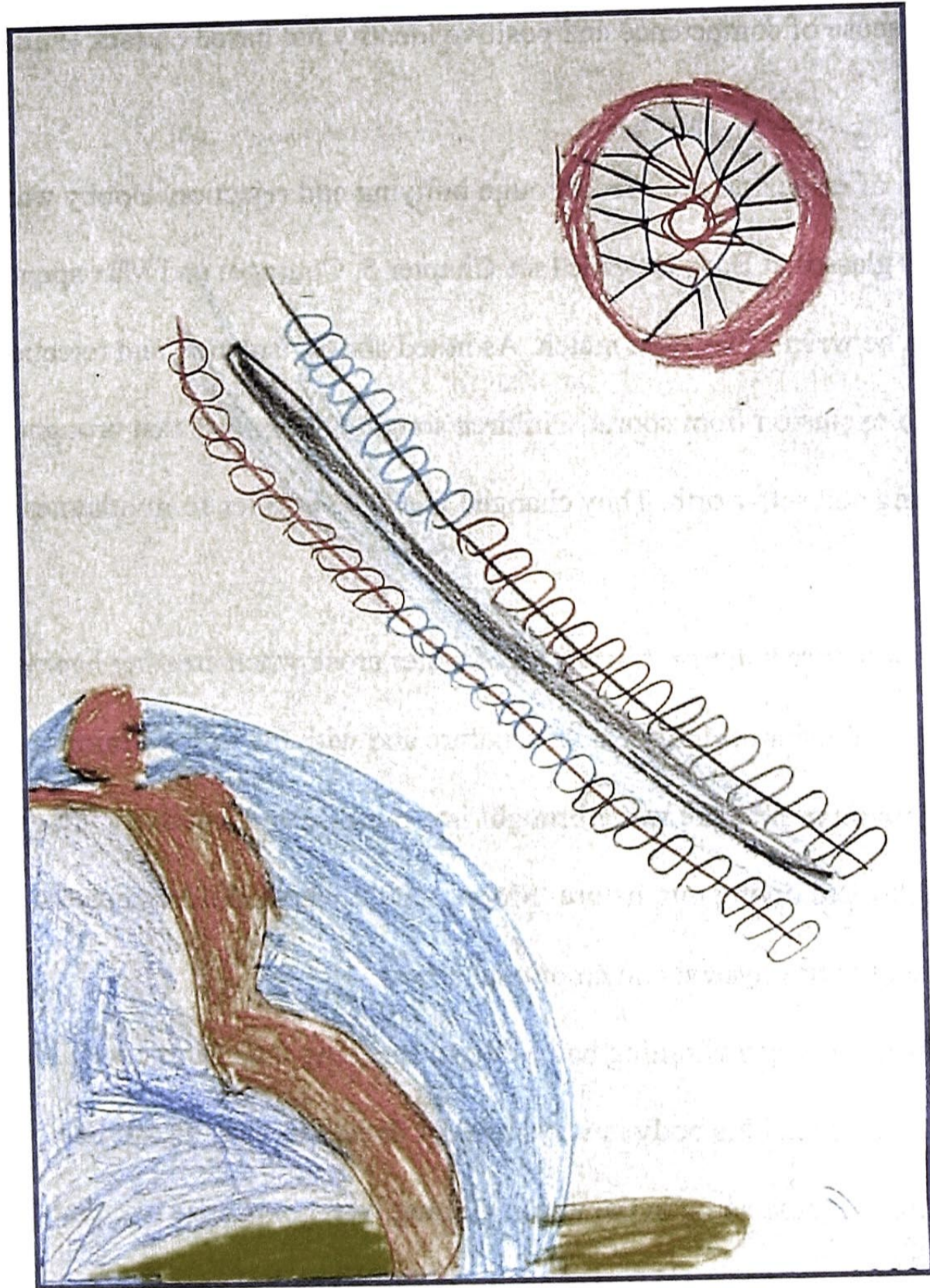
Deatherford played rugby. Chontelle was in a swimming club. For SSS007, swimming training in a local squad had layers of meaning, which included the benefits of movement and strength in his left arm. Groovy Princess played indoor soccer. Bobby did karate at Boy's Brigade. Michael Jackson played wheelchair basketball. Being a team member in a sport gave a sense of belonging not always found at school. The

children could participate as equals with other children. They could contribute to a team endeavour as a valued member of that team. Sport and leisure were domains where they could develop a sense of competence and positive identity not based on lack (Fullagar & Oowler, 1998).

Moments of exclusion occurred through bullying and rejection. Bobby was bullied about his glasses at Boys Brigade (see Chapter 5, *Courage*) and Max spent his time alone when he wasn't playing a match. As noted above, isolation and rejection also occurred through exclusion from sports. Children sought alternatives that brought a sense of belonging and self-worth. They changed their player roles from otherness to enfoldment.

Water and transcendence. Narratives of water arose when creating happy maps. These narratives enabled an enfoldment with nature and with the self. Swimming, surfing and playing in or near the water brought joy, purpose and creativity. There was a literal and metaphorical diving into nature (Moore, 2002) where children created a space of transcendence of their physical and emotional selves.

For Cerberus, going swimming had a deeper meaning than for most children. In the pool he could transcend his body in ways usually denied to him, "An' I like swimming lessons. . . . Just being in the water. Getting wet. . . . 'Cause like that, I can e'en lift up in the little pool. . . . I can e'en lift up and like hop." He could stand upright and move, with ability and mastery. He experienced a phenomenology of freedom as he experienced his body differently, a moment of transcendence and wonder. Barney had just started swimming lessons and was beginning to experience the joy of transcendence that Cerberus knew.



Drawing 6: Ian Welsh's 'Happy Patterns'

In our final conversation, Ian Welsh drew patterns of how he felt when he was happy. One pattern became an image of him surfing a wave (Drawing 6), "Surfboard and there's the wave. . . . They're my legs I'm up the back of the surfboard no that's the middle cause the, wait, comes out the back . . . The wave crashes over the surfboard and it's still there." He faced the challenge of riding a wave and not being overcome. He spoke of surviving big waves, "And then once I was running into a wave, I was running in towards it and 'pshh' and I came out the wrong end and then like, 'where's my surfboard'? And then I saw back there and like oh, oh tidal wave cause I, cause you were so close to the wave and it was so big and we were like, I ducked, I went underwater and it completely missed me." His narratives resonated with the power of the sea, with something big, close and potentially dangerous. The sea and Ian Welsh did battle, with him emerging from the encounter victorious, having outsmarted the sea.

Lisa engaged in (and took obvious pleasure in) imaginative storytelling and play while she was at the beach or the local swimming pool (Appendix R, p.360). This spoke of a richness in her being. Her creativity gave her pleasure, whether or not someone else was present. Perhaps it reduced her feelings of loneliness and otherness (see Chapter 7, *When people are mean*), and stimulated her imagination to create more complex and satisfying moments (Singer, 1973). These moments gave ways of acting out desires, of feeling empowered through knowing what could be created and having the control to alter the fate of what was created. She could be part of something greater than the self. As with Cerberus and his creative projects (see Chapter 6, *Nurturing the Self*), these enacted stories appeared to hold a meaning far greater than simple pleasure. For both of these children, there was an experience of flow when immersed in these realms of imagination.

Through leisure associated with water these children spoke of individual pleasures. Although Cerberus and Ian Welsh experienced mastery, their perceptions differed. For Cerberus, it was a transcendence of his gravity-bound physical form. For Ian Welsh, it was a hero's journey (Campbell, 1949) of battling and overcoming the power of the waves. For Lisa, times of creativity were formed within water. Although it was the same leisure activity, the experience of water had very different meanings.

Music and dance. Nina, Groovy Princess, Chontelle and Elvis experienced joy and creativity through music and dance. Groovy Princess was looking forward to dancing and singing lessons. Nina went to ballet and tap classes. For these children, music and dance enabled a transcendence of the everyday knowing of the self.

Elvis' favourite thing to do was, "To go to discos and stuff." This comment spoke of losing himself in movement and music, a time of transcendence. He became other than his 'disabled' self, belonging instead to a magical world. He spoke of it with a smile on his face and a brightness in the movement of his body.

Chontelle loved to go and see shows with her mother, "When, mum and I go to, the first time we went to, 'Disney on Ice', to see 'Snow White and the Seven Dwarfs'. I liked, I like ice skating people, I like ice skating, watching ice skating. So I like, I like the show, yeah." Dancing also brought her joy, whether it was watching others or doing it herself in front of the mirror at home. "Yeah, I like watching people doing dancing. I like watching people in Irish dancing. My friend, she do Irish dancing. Because when we went to camp, she, she did it, with bare foot." Through watching and creating dance, Chontelle participated in the transformation of her senses and ultimately her self. She

expressed her spirit through her own movement and her joy in watching others (Graham, 2002).

The joy experienced by children through water, music and dance reflects the flow of being when immersed in another world (Csikszentmihalyi, 1990). Other children had experienced flow through neighbourhood games and sport. These experiences enabled a transformation of self and a setting aside of their disabled identity as proscribed by society. They could move into another self, to be experienced differently.

Leisure can enable self-esteem through belonging, active contribution and purpose (Patterson, 2000). Leisure can be a source of identity, one created through agency and the imagination of being more than societal dictates (Fullagar & Owler, 1998). Leisure also has the potential to reinforce exclusion and otherness. The outcome is an interaction between children's self-esteem, the environment, opportunity, and encouragement from parents and peers (Aitchison, 2003).

Cerberus and Brett spoke of being excluded from participating in community leisure forums. Cerberus' difficulty in accessing aquariums occurred not only on school excursions (see Chapter 7, Part of the group) but on family outings as well. Although he enjoyed watching movies, going to a movie theatre was, "Too hard". Environmental barriers stopped him from communal participation in activities he loved. Brett was forced to remove his glasses in order to go on rides at the 'Wet'n'Wild' theme park. He told me similar situations happened, "All the time" making him frustrated and angry. Other studies have also identified negotiating environmental and social barriers as a common issue for children with disabilities and their families (Cavet, 1998; Law et al., 1999; Pollock et al., 1997). These barriers reinforced the disablement of the children's

identities, creating social identities not acceptable within the wider world. Such barriers are perpetuated by legislation that does not require universal access within leisure and community facilities (Gleeson, 1999).

Medical and Disability Services

All of the children in the study had extensive experiences of hospitals, health and disability support services. These services were an integral part of the lived experience of their impairment and interaction with the community. The children's narratives of their experiences were evoked when we discussed feelings and qualities. In contrast to classroom assistance (see Chapter 7, A special aide), these experiences were usually placed on their sad, angry and courage maps. Their placement on these maps highlighted the negative impact they had on their lives, and the spiritual qualities children needed to draw on in order to deal with these challenging experiences.

Knowledge through experience. Many of the children had a detailed understanding of their medical history and were aware of whether procedures or other interventions had been of value to their lived experience. Bobby had had many operations, "I've like 14 times." The operations helped, "Oh sometimes. Last year they were going to do them and they didn't really help." Children did not always accept the need for medical interventions, particularly if previous interventions had not helped.

Rambo saw doctors and physiotherapists for treatment of his spastic diplegia. He had just completed Botox injections in his calves and a series of plasters. I asked him about physiotherapy. He didn't feel it made a difference to his legs, "Nuh. It doesn't help." He said he had been going to physiotherapy since he was a baby but his legs were no straighter and walking was not any easier. He only kept going, "Because my mum

wants me to. She thinks, she thinks it's good. And it's not." As a child, Rambo needed to comply with his mother's wishes rather than being able to actively refuse.

Although he complied with going to physiotherapy, he chose to express his resistance by avoiding his home programme. He had to do exercises at home, "Sometimes. I wait to do it. I don't like doing it. It's boring." If he had a choice he wouldn't go to physiotherapy and wouldn't wear ankle-foot orthoses (AFOs), but would have an operation, "So I can walk." He'd had two hospital admissions for Botox injections, "Botox is [a] big [operation]." However, he would go through having Botox treatment again, "If I had to. It helps me." Out of all the treatments he had undergone he felt this had helped him the most. The discrepancy between Rambo's choices and those of his mother and physiotherapist were common experiences for children in other studies (Alderson, 1993; Bleeker & Mulderij, 1992; Missiuna & Pollock, 2000).

Deatherford was knowledgeable about his medications, their effect and impact on his learning (see Chapter 5, *An Alterity of Being*). Like other children with ADHD who had commenced medication, he met with a psychiatrist, "Mm, well I have to go to my, my, the person, who gave me the medication. And he asked me like, how I feel, on when, how and how the medication is helping me. . . . I just tell him." He was not privy to the conversations between his mother and the psychiatrist, "No, they don't tell me. Sort of like secret stuff. Well, I think they're asking about how I'm going at school. I think that's what, that's what I think but I'm not absolutely sure." The conversations were about him, but didn't include him, a child's position in the medical world (Alderson, 1993; Closs, 1998; Foucault, 1973). Like Bobby and Rambo, he was

expected to be compliant within rules established by others (Bendelow & Brady, 2002; Frank, 1995; Mayall, 1996).

Chontelle believed herself to be brave during her time in hospital for her cochlear implant. She received the implant, "In 2000, when I was 9." Before this she had, "Hearing aids" but her hearing, "Hearing aids, nothing" and with the implant, "Yeah, I can hear the radio"! With hearing aids, Chontelle had difficulty being understood by others, "Like people go 'What'?" She could only hear the main words of someone else's conversation. The cochlear implant had improved on this but she still missed words. She was to receive a new type of implant. Although her hearing wouldn't improve, "Still the same", she would no longer have a cord or a bag with a processor, "That will be good." Technology could give physical freedom. However, her use of this new technology was not a desire for invisibility of her alterity.

Chontelle drew a picture of what the new implant would look like, explaining the role and meaning of each piece. She talked about the ability to get interchangeable coloured external pieces with the new implant, an important consideration in a young girl's life, "I might get a purple . . . behind the ear. And maybe silver. You can put them different. Yeah, and if I wear clothes then." These options would enable her to make the implant a co-ordinated part of her beauty. Like Groovy Princess and her prosthesis (see Chapter 5, *An Alterity of Being*), Chontelle's new implant would become an expressive part of her being (Iwakuma, 2002).

Towards the end of our conversations, Ian Welsh attended a workshop at the Royal Institute for Deaf and Blind Children. He had participated in the workshop to learn further computer skills. What had impressed him was the on-site preschool, "And

there was also the best preschool you could ever go to." His excited wonder when relating what he had seen told me he had no prior knowledge that environmental adaptations existed for children with visual impairments. In contrast to his comments in an earlier conversation that he did "all normal things" (see Chapter 5, An Alterity of Being), this experience had impacted on his understanding of the value of knowledge. He had become interested in the knowledge available within the disability field, "Yeah if I was, if I, if there was something else I would go back and do it."

Seeing and hearing about these adaptations pleased him enormously, reinforcing the positive aspects of being with others who had similar impairments. He had a chance to 'see' the alterity rather than the otherness of disability as negatively defined in relation to normality. He found that disability services had something positive to offer him. The computer workshop opened up further ideas, enabling an embracing of the world rather than a distancing, "... and then I came back home and changed them on me [computer text into a larger font] and mum's getting all this special equipment, like there's this thing that you can put on your computer and its sort of like a huge magnifying glass and then there's also like little stickers that you put on the letters on your keyboard . . ." Knowledge of these adaptations gave the possibility of greater agency in his learning at school (see Chapter 7, Technology and wonder).

Keeta showed me a book of drawings, "And there's me and that, I drewed that. When I was going over the [Sydney] Harbour Bridge for the hospital." In this picture, she was sitting in the back of the car and she was winking. "And then I drewed about me going to the park. And I went for my other operation. *Yes, this is for your skin grafts and things?* That's when I was, I was getting my right arm done so I drewed that with my

right arm before I couldn't use it." Now, "I write with either." She had been right-handed, "And then I started doing my left hand. It was like, when this one [right] gets really sore . . . I had to write with the other one [once she'd had surgery on her right arm]." Keeta creatively adapted to her physical difficulties so she could still write and draw, constructing knowledge of physical adaptation from her experience. In drawing, she found an important avenue of emotional expression within the difficult and painful experiences of medical treatment; an expressive avenue she was determined to maintain.

Meeting the challenge. Going to the doctor, dentist, or to hospital were often placed on children's courage maps. Barney thought she was brave when she went to hospital, even though she got scared, "A little bit." Rambo's brave map was red. On his map he wrote 'needles' because he was brave when getting Botox injections, feeling "good", "calm" and "Sometimes, sometimes scared." Experiences of being ill, going to hospital or having an operation were also placed on sad maps. For Bobby, having operations on his eyes, "That makes us sad probably."

Keeta's passion for drawing had continued throughout her initial hospitalisation. Her mother told me that Keeta continued to draw even when she could only use two fingers. As her fingers became more necrotic, "I, I just, they just sort of, when they were there the black stuff started to melt onto the pencil. And it got stuck." Keeta lost thirteen fingers and toes, which just, "Fell off. . . . It didn't hurt." She and her mother had laughed about it. Bobby used black humour when talking about his glaucoma, laughing when telling me his eye had 'exploded'. Both children experienced resilience through humour.

Michael Jackson and Chontelle had pain-filled memories of medical procedures.

Michael Jackson's mother told me that in his life he'd had twelve sets of plasters. The rigours of pain and discomfort that were part of dealing with his physical impairment were well known to him. I asked him where he would place having an operation in terms of his feelings, "That would be really angry cause it really hurts. Pain. We could write that down, pain. Painful things. I've done it twice. I had one on my foot and my quad, and then I had of the two hamstrings and my right calf." Operations were eventually placed between sad and angry.

When Keeta was in hospital, she initially trusted the doctors and nurses, "Cause I wanted to." This trust was betrayed, "But they used to tell all my secrets. The doctors . . . Some of them did but some didn't. Because they said 'I'll just tell your mother'. And I said, 'No'! It wasn't about hating or anyone. It was just about how I was scared a bit. And I stopped telling secrets." This betrayal of trust had caused her to approach all medical and health professionals from a position of distrust.

The children shared common experiences of pain and discomfort during operations, medical procedures, and often therapy. They experienced losses of privacy, dignity, and limited respect for their emotional needs. These experiences often left them feeling vulnerable. They were reliant on others for their physical wellbeing, needing to cope with their own emotional needs. Their positioning within the medical world reflected the institutional power with which they were expected to comply as 'docile bodies' (Foucault, 1973; Mayall, 1996).

Michael Jackson and Rambo talked about liking their physiotherapists. Cerberus talked of his Speech Language Pathologist, Keeta of an ICU nurse, and Chontelle liked her specialist. However, Bobby was the only child who placed a medical person on his

trust map. He told me he trusted his ophthalmologist because he had to and wanted to. The absence of other children's narratives of medical and health professionals who populated their lives speaks of a lack of relationship. Children were unable to challenge the power of these relationships, and were often unable to establish a sense of connection or the receiving of respect. The positioning of experiences on courage, angry and sad maps indicated these times were to be feared.

I asked Keeta what she would say if I was scared about going to physiotherapy, "Say you were going to physio, it doesn't hurt but . . . Well a little bit but you'll get used to it and then you'll want to go and the doctors [physiotherapists] are very nice." She thought it helped a little if, "Mum, dad and your favourite doctor" were there, "Cause then you've got all your friends around . . . It would make him more, braver." Knowing there were people who cared would enable resilience through connection (Hunter, 2001). Finally, "Having a little pet there, like a mouse or something." as she was able to have a visit from her bird (see Chapter 6, Pets as family) "Yeah it was heaps good." Being able to have the company of a favourite animal, a special friend, could bring love and belonging, providing a supportive emotional embrace.

Keeta believed adults needed to be, "More careful. More respectful. Respectful" in their interactions with children. We also needed to be careful, "In what you [adults] say." She believed that if the doctors had been respectful towards her they wouldn't have told her secrets to her mother.

I asked Elliot what adults who helped children with disabilities should remember, ". . . the kids should trust the adults. And they [the adults] should just respect the kids and, and they'd show the kids the trust that they want." For Groovy

Princess, "Oh just try your best" was the way to try and trust others, "You'll just hope that they trust in you and you can trust in them." She described trust as, "Trust kind of means like oh when you've got to just try and believe in someone and yeah. Just try and believe. And another word for it is believe." Like Keeta, these children desired respect and trust from adults.

SSS007 had had four operations and spent six months in plaster. Although he had experienced major upheavals and pain in his life, he had not been perturbed by these experiences. When I asked him what helped him to cope, he replied, "I just believe in Jesus. I can trust him. That he won't, you know, let me get hurt. And not be scared." He appeared pragmatic and unshakeable in his religious faith, and this sustained him. Praying to God and asking to be taken care of when he had an operation gave him the courage of self to meet these challenges. Prayer gave him support and care, enabling resilience through trust (Koenig, 1997; Wright & Sayre-Adams, 2000).

Many of the children attended mainstream schools (Appendix M) and did not know other children with similar impairments. Groovy Princess attended hospital outpatient clinics where there were other children, "Yeah with other stuff." She only knew two other children with spina bifida, one of whom was a girl who also wore a prosthesis. I asked her whether it would make a difference if she were able to talk to other children, "I think it would be a good difference cause then you could talk about your problem." To meet and talk with others could enable a "sense of understanding that could only be established through shared personal experience" (O'Connor, Young & Saul, 2004, p.212).

Brett found a 'sense of understanding' depended upon meeting others who

shared his personal philosophy. He had participated in two camps for children with disabilities. Meeting other children with disabilities had positive and negative aspects, "It's yes and no because, well, some of them, just like, are just, they can't live with, what they've got or something, and the other ones just, good. Some accept it and [some don't]." Brett had found another child who was happy to talk about his impairment and how he felt but, "I, me and someone else tried to, but the other ones, they just, they just kept changing the subject. I'm not sure if they liked, that kind of." He was able to share knowledge, experiences and feelings with another who like himself, 'accepted' his impairment.

For other children in the study having their pain 'witnessed' (Fleischman, 1994; Frank, 1995; Wright & Sayre-Adams, 2000) by another was important. Being able to express their fear, sadness and anger, and having these feelings honoured helped to ease their emotional distress. The empathy of another for the physical and emotional pain they were experiencing bringing a sense of connection in the aloneness of suffering (Peloquin, 1995).

The support each child brought into being within these experiences reflected their personalities and the unique meanings they found within their lives. Religious faith, being able to continue activities, talking with others, using humour, having a pet and other 'friends' with them, being shown trust and respect all contributed to their resilience in meeting these challenges. All of the children responded creatively to the challenges they faced (Rowles, 1991), seeking to meet their needs in ways that reflected their personalities.

Many of the children were pragmatic about what had happened to them and was

happening for them, as were the children interviewed by Bleeker and Mulderij (1992). The children in this study had often spent long periods in hospital and in rehabilitation programmes. Similar to the children interviewed by Krementz (1989, 1992), these children were knowledgeable about their disabilities, treatment and outcomes. They were reflective and voiced their opinions. Their informed views on medical procedures reflected the understandings of children interviewed by Alderson (1993). The children in this study actively sought their own coping strategies and voiced the need to be respected.

They showed courage (Tillich, 1952) and wisdom (Alderson, 1994) in meeting the difficult and confronting experiences of their impairment. These experiences became part of the everyday. Their narratives were told as another experience in their lives rather than the focus of their lives. These experiences did not control their lives, but did impact upon it in terms of pain, discomfort, and time away from home, school and leisure. They expected their involvement in medical and disability services contexts to be an ongoing part of their lives.

Religious Faith

Asking the children what and who they believed in usually evoked narratives of religious faith. Happy and faith maps raised expressions of belonging and support through religious faith. All of the children identified their cultural belonging within a Christian faith. However, their perceptions of the influence and support of their religious faith within their lives varied. Ian Welsh's religious faith appeared to be in name only. For SSS007 and Cerberus, religious faith was intimately enfolded with their lived experiences.

Happiness and belonging. When I asked Barney what made her feel happy inside, she replied, "Jesus. He makes me happy because I love him." Her happiness was gained through love for another. Chontelle believed she made God happy. Faith for Bobby meant, "Believe isn't it? I think so." He drew his faith map like the four arms of a cross with God at the top, Jesus to the left, the Virgin Mary to the right, and his parents at the bottom. He drew the faith in others that supported his life (see Chapter 5, Stories of Origin).

Because of the importance of religious faith in SSS007's life, early in our conversations I suggested to him that we each do a faith map. He drew the word faith in large letters, making the T into a cross and placing eyes and smiling mouths on the I, T and H, with the H also receiving a nose. Faith, "Makes you feel more happier than you were happier." This feeling of joy was experienced in his, "Soul and heart." He also wrote the 'Ten Commandments' and 'life'. His religious faith was an integral part of life and living the Ten Commandments a way of expressing this faith.

Brett talked to God through prayer, "Sometimes. Every, every lunch time, and oh cause we say a prayer to Him [at school], and every night." God didn't talk back to him directly, "Oh in a way. Not, you can't hear Him, but in a way, yeah." He believed God replied through the events that happened in his life, through his experiencing of God's grace. Through prayer, Brett related to God in an engagement that was lived within his world (Moore, 2002).

Cerberus and his family had a strong Catholic faith. His parents taught scripture at his school, his father worked for the local church and their home had small altars and icons. For Cerberus, this religious faith provided protection from harm, and a sense of

belonging and being cared for that was very important to him. When we were drawing our happy maps, the first thing Cerberus drew was a face and arms representing God. This representation spoke of being welcomed and embraced. God made him happy, "Outside and inside." He made him happy 'outside' because, "Well, I know He always there." There was a giving of protection and an assurance of divine presence in his life.

Elvis believed in, "... all the people where God is and all that. And Jesus." In our conversations, his Christian beliefs and understandings of its teachings didn't appear to translate into connections with his own life. Although religious practices were part of the rituals of his family life, there wasn't a sense that his religious faith gave grace or purpose as it did for Cerberus, SSS007 and Brett. However, like Cerberus it gave him the sense of belonging to a larger family.

Participating in religious rituals gave opportunities for joy and belonging on a human level as well. Elvis saw school friends at Sunday School. Nina engaged in art and craft at Cell Group. Brett attended church with his mother or grandmother. As noted in Chapter 6 (Celebrations), attending church and participating in Christian celebrations enabled times of belonging with family and community.

A source of support. Brett's perceived his religious faith as, "It just helps me to learn." His religious faith helped him in other ways, "Well, it, teaches me to believe and stuff so, I can ... be strong and stuff, yeah." Religious faith meant, "It means, it means to be, just teaching me to be strong and to keep going on with my life. That's what faith is. And I believe in fate, fate happening, yeah." In his life, fate meant, "Oh, I'm not really sure. It means, oh have luck and you've got to have faith to get fate. That's what I believe anyway. You've got to have faith in somethink, or in a religion." Religious faith

provided support and a purpose to life, and enabled him to receive grace in the form of 'luck' and 'fate'.

Cerberus' religious faith protected and supported him in many ways. His night fears (see Chapter 5, Courage) were lessened by the presence of his grandfather, who had died when Cerberus was little. He knew his grandfather through his mother's stories and family videos. He could feel his grandfather's spirit at his grandmother's house, "And, and everywhere, everywhere." He had others to protect him as well, "Well, I got lots of people. . . . I got God, Jesus, Mary . . . my guardian angel . . . [Name Saint] and my nanu." Their presence was stronger at home, but he also knew they were with him at school. These presences came from the support he found within his religion, a strong and supportive mystical group that cared for and protected him.

SSS007 found Bible stories helpful if he was angry or agitated, "It helps me calm down and it's interesting." He especially enjoyed reading the stories of his name saint, "And I'm from the Bible. And that's interesting what he done." His name saint provided a role model of kindness and leadership in which he could lose himself, to counterbalance the moments that brought agitation (see Chapter 6, Nurturing the Self). As SSS007 sought to understand the world and the actions of others through his religious faith, his comments resonated with St Augustine's "linking of reason and faith in the pursuit of philosophy (wisdom)" (Groeschel, 1995, p.45).

SSS007's religious faith was also valuable to him when he was scared, sad or doing something difficult, "Yeah, most of the times it helps. Well it's because I learn more things, how to be like more controlled and how I can tell other people about Jesus like they did in the Bible, like [Name Saint] did, so I will do that. And I will tell some

bullies, like a boy [at school]." (see Chapter 7, When people are mean). His religious faith helped him to deal with his feelings and gave him guidance (Koenig, 1997). Elliot had spoken of courage being received from God (see Chapter 6, Acts of courage). Like SSS007, Elliot's religious faith supported him in difficult times.

Reasons to believe. Like Brett, Elliot believed God supported him, "Well I believe that He's good. I believe that He makes the right decisions for me. He will do the things I want to do that are not bad. He'll help me make the right decisions, not the wrong decisions." Although he didn't go to church anymore, he did pray, talking to God about what was happening in his life, "Yeah. And I sometimes pray that He can make things better, like my temperature [he had a high temperature this day]." His God was a god of daily life, of understanding and support.

Groovy Princess' religious faith understanding encompassed the reason for her disability, "Just like all different stories about like God didn't make everyone perfect. If He did want them perfect He would . . . Cause He didn't want to. He made me with a disability because He wanted everyone different and He made, say you, you have something, or He did something, made something for everyone to have special . . . Even brothers and sisters, we're not really the same. We may look the same when we're younger and things but we aren't." Her narrative spoke of the uniqueness of each human being, a philosophy shared by SSS007 (Chapter 5, An Alterity of Being). Within this uniqueness was a purpose for her impairment, of God's plan for her, which resonated with Elliot's story of origin (Chapter 5, Stories of Origin).

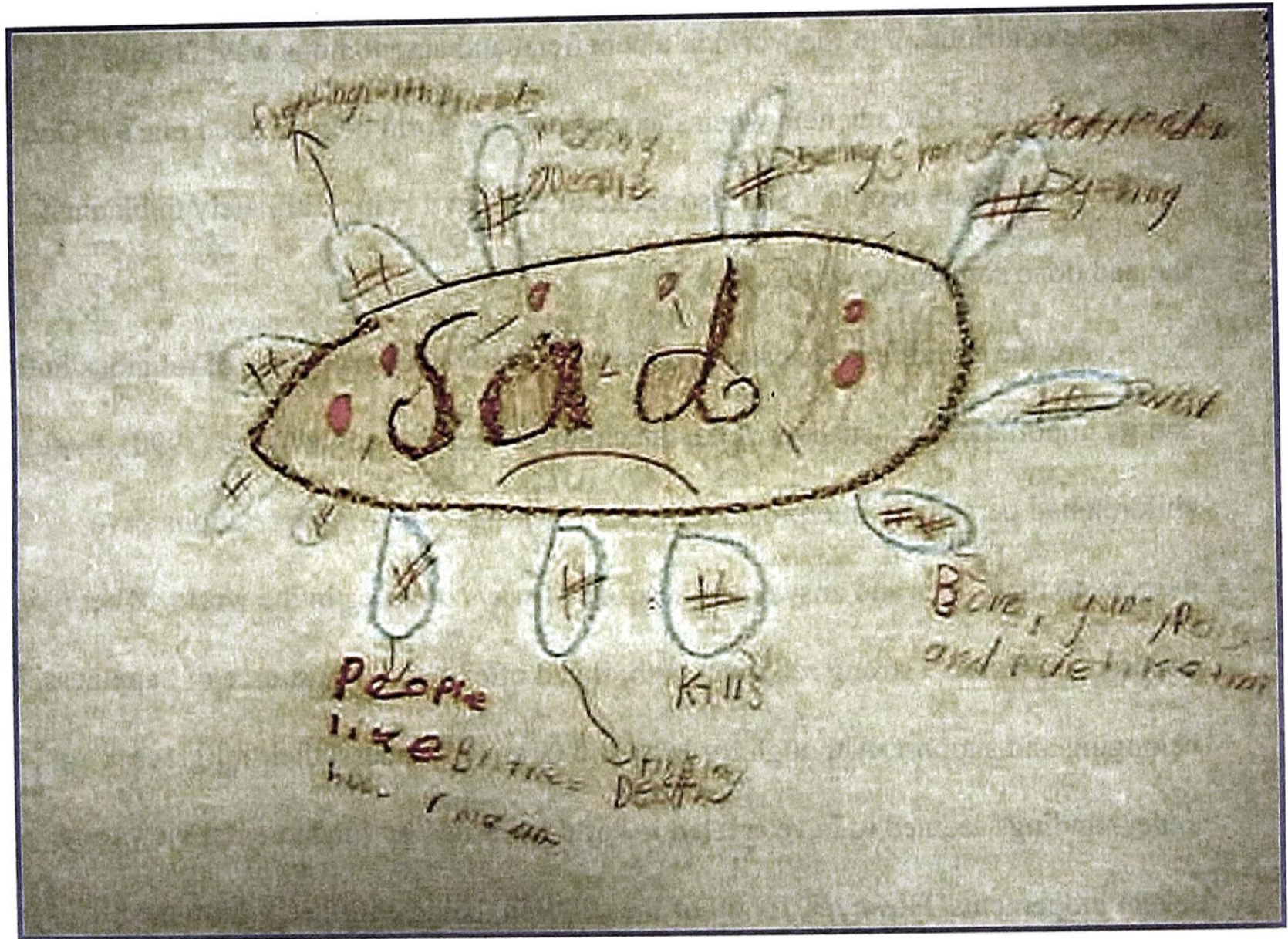
When I asked Max what made the world a good place, he replied, "Of course you should know. *What?* Who lives up in heaven? *God?* Yes." And when I asked him

what made the world a bad place, he exclaimed, "Who lives down in hell"! This was the beginning of a lengthy narrative where Max's beliefs seem to reflect fundamental Christian teachings accepted as truth rather than those he may have pondered for himself and discussed with others. In his narrative, there was no sense of personal causation, or of people contributing to the world in a beneficial and autonomous way. Groovy Princess echoed Max's beliefs when she spoke of the world being a good place if God "killed all the nasty people". She also spoke of the Devil being ultimately to blame if she had done something wrong.

For the children in this study, there were many lived meanings of religious faith and its importance in their lives. Like the children interviewed by Coles (1990), these children had personally interpreted religious teachings. Their interpretations gave purpose to their lives and answered questions of ways of being in the world. Where children expressed a strong religious faith, it had often become a source of happiness, belonging and support. Although for Max and Groovy Princess, their religious understandings seemed to have created a world governed by fundamental views and severe judgements. However, for all of the children, being enfolded within their religious faith brought connection with others. Religious understandings contributed to children's ethics and world consciousness, creating an awareness of the needs of others.

World Consciousness

Compassion for others. I asked the children what made the world a 'good' or 'bad' place. Their reflective narratives expressed their consciousness of the needs of others, world conflicts, and the impact of alcohol and drugs. There was a common desire for world peace. They were conscious of the environmental issues of pollution and



Drawing 7: Groovy Princess' Sad Map

global warming. Issues that concerned them were also raised when I asked the children what the world would be like when they grew up, or what they would change about the world. Their thoughts appeared on feelings and qualities maps, and in their three wishes.

Deatherford's three wishes related to his desire for justice and harmony in the world. His first wish, "If the world was a, much happier place, then, than what it is so far, I mean so if it didn't have any, as many people doing horrible things to other people [like war]." His second wish, "probably that, that, ah, people wouldn't, like steal things or take things from other people, that people really, really, thinks that's really special to them." And his third wish, "And, that, if, that, people would, like, be kind to other people, and, like not, not, not bully them or something, and, and, and so that, just so, so if they bully someone they will get into trouble." Many of the children voiced a desire for people to be kind and helpful to each other. Deatherford's desire for justice was also echoed by other children. People needed to be responsible for their actions and experience consequences for their bullying.

Elvis felt angry when people were mean and when they stole from others, echoing Deatherford's sentiments. The importance of justice for people who were wronged was raised when he spoke of Amnesty International (AI), "Some people could go to gaol for like doing something they didn't do . . ." Elvis saw the presence of AI as one of the things that made the world a good place. For him, the world was a place where organisations could right the wrongs that happened to those who were powerless.

As we started our sad maps, Groovy Princess admitted she got sad a lot. She drew large blue teardrops around her sad circle (Drawing 7), "My sad feelings - fighting with friends; missing people [who had left]; being smacked or grounded; yelling

[anyone yelling]; war . . . Bombs, guns, poison and more like that. Kills [people killing each other]; thinking of death [anyone thinking about it or talking about it]; people like [Friend], how, who are mean." Many of the children voiced their distress over "the problem of evil" (Matthews, 2002, p.11) evidenced in killing and war, with a philosophical need to understand 'why'.

Ian Welsh's concern reflected his sense of humanity and his compassion for the suffering of others. He thought, "People who are poor should be living in homes and stuff like that." He voiced his compassion for others and his awareness of the world around him. His concern for the homeless was shared by Max and Brett. When I asked Ian Welsh for his three wishes, his first wish was, "To try [and] stop wars or something like that, to be powerful enough or like a magician or something to stop something like that."

Elliot's narrative, in reply to my question about what makes the world a good place, reflected his philosophical views on the importance of compassion and caring, "Not hurting people, helping people when they're hurt, just helping people do their homework, even picking up rubbish. Those are the things that make the world a good place." His views echoed the views expressed by many of the children. For example, Chontelle spoke of her anger over current international conflicts, drugs and littering. Brett and Nina voiced their concern over global warming.

Through their concerns, the children positioned themselves as members of the world community. In their narratives, they raised issues of community disconnection through war, pollution, stealing, etc. They expressed their desire for community love and belonging through world peace. The children's consciousness and compassion for

others and the environment reflected the narratives of the children interviewed by Coles (1986, 1990). The children interviewed by Coles and the children in this study spoke of their concerns over people's unkindness and disrespect towards those who were vulnerable. As all of these children experienced such attitudes towards themselves, they perhaps had a greater consciousness of the need for people within the global community to offer kindness and respect towards others.

Respect from others. Narratives desiring respect from others were told by children within our discussions on many of the topics. Experiences of disrespect ranged from being stared at when in the community to the naming of community organisations. As with their school experiences (see Chapter 7), the children were conscious of the need to respect others and felt they should be accorded the same measure of respect. Children also voiced ways in which they sought to be respected.

As Rambo's mother talked of the lack of services at their local children's hospital and needing to access The Spastic Centre of NSW, Rambo vehemently said, "I think that's rude calling it the Spastic Centre. That's [spastic] offensive. Such an old fashioned word. I'm going to tell that lady next time I go . . . I'll tell them again. And I'll give them that fax number this time. I'm going to write a letter tomorrow after this, when I come back home." The organisational face of his impairment positioned this aspect of his physical self within 'offensive' terms. He was not prepared to accept this negative labelling, wanting to voice his anger over this disrespect.

Elvis expressed a strong dislike of others staring, highlighting feelings of otherness, ". . . but it's just my own business, they can mind their own. Some people stare at me like I'm, but I'm not, I'm exactly like they are, well, not, well, I can do

things like they can do, I'm not like can't do anything, well I can do, so, kind of hard being disabled, cause I can't really do very much by myself." Other people staring and asking questions placed him as lesser, as not capable. Their responses seemed to reaffirm to him that he was dependent and other. Community attitudes diminished his way of being and he became negatively conscious of his body (Bleeker & Mulderij, 1992; Williams & Bendelow, 1998).

Elvis was struggling with his sense of himself being the same as everyone else, a human being. He lived within a society where he had an alterity of being not recognised or accepted by others (O'Connor et al., 2004). When he went into the community he was not seen as a child who very competently *used* an electric wheelchair for his mobility but as a child *confined* to a wheelchair, which placed him as passive and to be pitied (Zola, 1993).

I asked Deatherford what adults needed to understand and remember about children. He replied, "Like, always have, like always think before you act or something. And don't ever give up [on kids]. Is that, that, that, something has, like, something, aren't, this person has done, is doing something with, like on medication or something, and so you've got to be like, oh sort of, sort of, I mean like, like say that someone's, on, on like, sort of medication and, like which, like say if they're deaf in this some one ear, they have medication or something to try and make sure, make it that so that like if they're like hard hearing in this ear, they take medication or something to try and make, make, make, make the ear feel better, you've got to try and like not, not, speak too softly, you've got to try and speak up a little bit, so that they can hear you. Yeah like you just, that was sort of that what's kids should do as well [pay attention to what

they're doing], as well, because if like, like, if you, if like someone's talking to you, you don't just like look over there or something, like and watch something else like . . . they think that you're not listening or something."

The wisdom of his narrative was a strong reminder to adults to think, take care, be helpful, pay attention to children's needs, and to understand the effects on self and the constant negotiations of disablement in our society. All of these behaviours would show children respect.

Groovy Princess thought it was important for children to have someone to talk to if they were experiencing problems, "But they would tell, like if I thought it was okay for them to tell mum then they would. That's what [Counsellor] did anyway. Cause if they go on like telling mum and then getting mum sick about things that I don't want her to know then that's quite bad. But she always asks. Like 'Is there anything that you don't want me to tell mum'? You know, a phone call or anything. Yeah there might just be and this kind of thing." Groovy Princess' counsellor accorded her the respect Keeta had desired (see Meeting the challenge, above). Like Keeta, Groovy Princess expressed her view that all children needed to be shown this respect.

These children felt respect needed to be shown through language used, modes of interaction and boundaries of privacy. The lack of respect they and other children experienced evidenced a lack of love, belonging, compassion and consciousness from others. Within many of their community contexts "the widespread practice of adult disrespect for children" (Brannen et al., 2000, p. 33) needed to be navigated. They needed to draw upon their spiritual qualities of love, trust, faith, courage and ethics to sustain their identities as respected members of the community.

Implications for Practice

The world is always our world, understood and constructed by ourselves, not in isolation but as part of a community of human agents, and through our active interaction and participation with other people in that community.

(Moss & Petrie, 2002, p.20)

Children's community spaces include those of their neighbourhood, leisure forums, medical and disability services, and religious faith communities. These are spaces of active negotiation in which children seek to express their identities and to which they contribute. Children, like adults, see their participation as a valued part of life within the community. Their participation enables the possibility of avenues of agency and avenues of belonging. For the children in this study, community participation also raised issues of isolation, disrespect and vulnerability. Acknowledging and addressing the diversity of children's emotional experiences is important when enabling them to interact with the wider world.

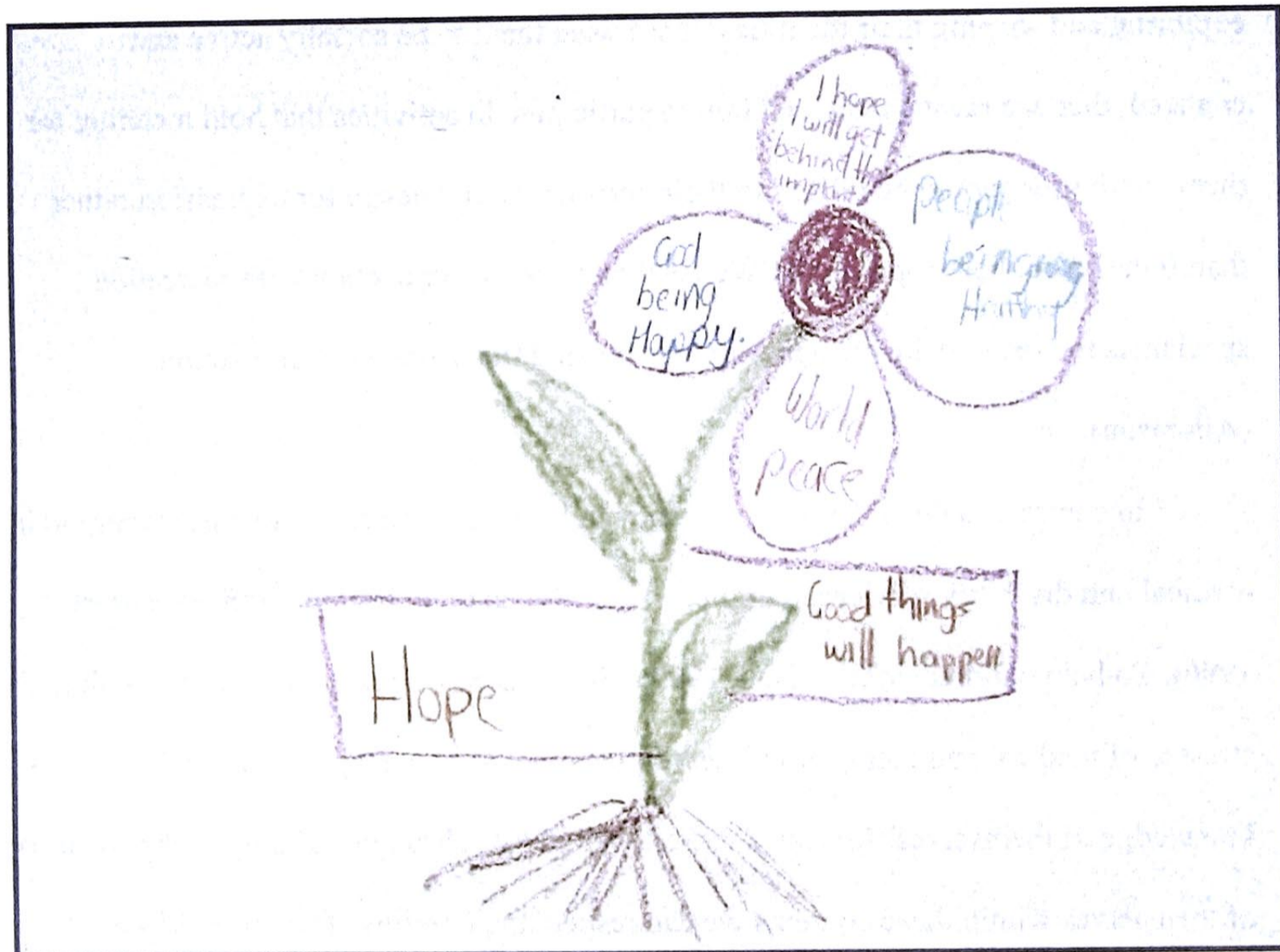
Through sport and recreation children facilitate their own performance and development rather than these being constructed through therapeutic means (Aitchison, 2003; Hinojosa & Kramer, 1999b). They are the agents of their own 'learning'. Thus, leisure enables avenues for seeing the self as agentic, and avenues of sharing skills, and giving dedication and support to/for others. Whether within a neighbourhood or in organised sport, participation in community leisure creates possibilities for the forming of friendships. Children can develop their intrinsic motivation, and experience joy and challenges, through participating in activities that have no goals but pleasure in and through the self.

As occupational therapists, we need to enable children to experience "leisure as 'freedom to' engage in activities of choice, in freely chosen spaces, for positive benefit"

(Aitchison, 2003, p. 963). Careful consideration needs to be given to leisure activities in the lives of children (Howard, 1996; King et al., 2003; Specht et al., 2002). Engagement in activities enables belonging, purpose, joy, creativity and transcendence. Through being with others, discovering more about the self, and extending the self, children are exploring and shaping their identities. If we wish them to be socially active and engaged, then we must enable children to participate in activities that hold meaning for them. Activities should be related to their personality and desire for expression rather than focused on their impairment. We need to work in conjunction with recreation specialists to create inclusive opportunities beyond the therapeutic interaction (Aitchison).

In contrast to the potential for agency in leisure, children's active participation in medical and disability services is limited. Their role is to be compliant (Shakespeare, 1996). To help children cope (Olson, 1999; Williamson & Szczepanski, 1999) with the stresses of medical and therapeutic interventions, we need to respect children's knowledge of themselves (Missiuna & Pollock, 2000). Through listening to their stories of themselves within these contexts we can respect their feelings (Fulton & Moore, 1995; Peloquin, 1993). We have an ethical responsibility to add to the knowledge they seek of what is happening to them and the possibilities available for them (Alderson, 1994). Most importantly, we need to respect their efforts to be actively involved in this context of their lived experience.

Peloquin (1993, p.830) suggested that, "helpers fail to recognize that illness and disability are events charged with personal meaning." We need to respect the sadness and fear children experience, and the courage and trust they need to draw upon in order



Drawing 8: Chontelle's Hope Rose

to cope. Children must be able to have access to what gives them comfort and resilience, such as friends and family, religious faith, activities and pets. We must support them in continuing to engage in activities of personal meaning and expression (Fulton & Moore, 1995). Ultimately, we should seek to collaborate with children on ways of implementing intervention goals that respect their physical and emotional needs, and their desires for themselves (Missiuna, 1998; Peloquin).

For some children, religious faith is an important part of their lived experience. Their religious faith enables them to cope with pain, sadness and loss, providing emotional strength in difficult times (Coles, 1990). We need to respect the support children may derive from their religious faith by enabling children to engage in religious practices, such as prayer or Sunday School. The sense of belonging that may occur within a religious community needs to be maintained and respected, and the diversity of religions acknowledged.

To respect children's desires for themselves and the world, we must remain conscious of the concerns children have. Enabling children to express these concerns will help us to understand the interrelationship of their daily concerns with world concerns. Understanding how these concerns impact on their identities and how they cause children to draw upon their spiritual qualities will tell us of the impact the wider world has on children's sense of self.

Chontelle chose to draw a flower to represent hope, "I'm making a rose" (Drawing 8). The leaves of hope were, "... good things will happen." From the stem of the flower four petals spread wide, each with their own hope; "Sometimes at school people say world peace. I hope I will get behind the [ear] implant, people being healthy

and God being happy. I make God happy.” Her rose enfolded her awareness of the world and humanity, her ongoing medical needs, and the meaning of religious faith in her life. Her drawing captured her hopes for herself and others, which were echoed by many of the children in the study.

Chapter 9: Conclusion

There is no such thing as a small story.

(Chai, 1996, p. 8)

Children participate in multiple contexts that shape their identities and call upon the embodiment of spiritual qualities. Children's identities are affected by the world in which they live, how they perceive the world, their responses to the world and the responses of the world towards them. Children's responses to the world come from their interaction with the world as that interaction is profoundly shaped by everyday spirituality. The contribution of their spirituality to their sense of agency is a neglected area of knowledge in adult understanding, and one in which children have had limited opportunities to voice their knowing of themselves and their lives.

A child's self cannot be separated from the world, as it is through the world that the self finds its expression. The same set of circumstances may be experienced differently by different children due to the characteristics of the self, which are built on the foundation of the spiritual resources upon which each child is able to draw. A child's experience of his or her environment and interactions with others as enriching or limiting will also call upon the resources of the self, and will assist or hinder the ongoing development of the self (Bronfenbrenner, 1979; Coles, 1990).

Children's interaction with the world is not simply a response to external events; rather it is an interaction between their knowing of themselves and the world, and the world's interaction with them (Merleau-Ponty, 1964). Children's lived experience seeks an expression of the self that is accepted and fostered by others in their world, and, in turn, seeks to connect with others in ways meaningful for both.

This chapter summarises the key theoretical concepts, analysis and discussion presented in the body of the thesis. The stories of each of the 18 participants were a multifaceted expression of identity and the embodiment of spirituality. The richness and complexity of each child's stories ask us to listen carefully and reflectively to children. Their stories remind us to respect children's understandings of themselves and the world in which they live. There are no small stories.

Reflections on Knowledge

Reflecting upon social and cultural constructions of childhood, leads us to reflect upon the professional understandings occupational therapists have of children and of children with disabilities. Exploring key concepts from the diverse disciplines of phenomenology, psychology, psychiatry and sociology creates an alternate space within which to consider our knowing of and relations with children, extending our understanding and ability to respond. Bronfenbrenner's (1979) ecological model provides a beginning for understanding the social and cultural influences on children's lives, influences that weave with the construction of identity, of their being in the world (Merleau-Ponty, 1962).

There has been a lack of occupational therapy knowledge of the negotiation and meaning of identity for children with disabilities. This lack highlights a need for research that enables children's voices to be heard rather than privileging the evolution of theories based on adult perspectives of the world of children. The additional absence of spirituality within constructions of childhood leads to the lack of a deeper understanding of children and their lives. There is an ongoing need for an understanding of how children view themselves and their lives, and an urgent need for an awareness of

the spiritual relation between identity and the world, in which the self is acknowledged as an active agent drawing on spiritual resources in relations with self, others and the world. When we reflect upon these needs we consider how spirituality is embodied to create agency, resiliency, motivation and an engagement with the world central to identity formation.

If children are spoken into being only through our traditional theoretical knowledge base, then they will remain within that truth for us. Here children are only allowed to respond to the picture we have created of their identities (Bollnow, 1989a). If, however, children express their identities and are listened to with empathy, then we can begin to enter into relationships with children where we better understand their way of being (Piper, 1999). This thesis assumed we need to connect at the level of spirituality, both children's and ours, for relationships to be empowered for positive change (Peloquin, 1995). In these relationships, children must be able to trust that we are respecting their identities (Bollnow, 1989; Davis, 1998; Toller, 1999). From this perspective, the thesis explored and described the construction of relationships for children with disabilities and synthesised what could be learned from this approach.

Reflections on Listening to Voices

Through their conversations, the children constructed their knowing of themselves and their lifeworlds. They positioned themselves within their families, peer relationships, communities and society through stories of importance and devaluing, of agency and invisibility. Ultimately, they constructed their identities and their truths through what they did and did not choose to share with me. Through their narratives, the children challenged the cultural narratives of disability, of children with disabilities

being situated as "passive, vulnerable and dependent" (Davis & Watson, 2002, p.159). They expressed their spirituality; speaking of their desires for their lives, how they perceived themselves, and how they perceived themselves in relation to others. They spoke of their desire for respect from adults and other children, their sense of power over their own lives. Their narratives resonated with reflexivity and agency.

Hermeneutic phenomenology (van Manen, 1990) enabled an exploration of the connection between the literature on spirituality and the meanings embedded within the children's narratives of themselves and their lifeworlds. I used narrative conversation (Ricoeur, 1992; Riessman, 2002) to elicit and explore the children's experiences. I joined this method with hermeneutic phenomenological analysis (van Manen) in discovering the meanings of these stories. Drawing on these approaches unfolded the meanings of the self the children experienced, rather than those proscribed by the culture and society in which they lived. Using these methods enabled a reflective approach to children within a research context, one that respected their voices.

Within narrative conversation, the use of metaphor (Lakoff & Johnson, 1980; Potter & Wetherell, 1987) was also considered as the children spoke of their lives and of others through metaphor. For example, Deatherford spoke of sameness and difference through mathematical logic, Lisa spoke of happiness through her love of horses, and Cerberus spoke of courage through mythical and religious stories. The children's metaphors were contextually situated within those experiences that had meaning in their lives and their engagement with the world. The children's use of metaphor reminds us it is important to listen for the embodied meanings of metaphors in stories. The

'unspoken' meaning of metaphor takes us beyond the literal level to a fuller understanding of children's lives and identities.

Hermeneutic phenomenological thematic analysis (van Manen, 1990) of the children's transcripts revealed common themes in their lives. The children expressed themselves through narrative, in its broadest sense, the creation of drawing and artwork, the sharing of games, and the photographs they took and others they shared with me of the important people, places and things in their lifeworlds. The focus of their lives, their hopes, wishes and dreams, their resilience to adversity in the daily milieu of their lifeworld, and their belief in themselves wove together in their expression of their being. They became passionate, sad, joyful, angry and bewildered about the experiences impacting on their lives, philosophically seeking to understand the meaning of these experiences and the 'whys' of others' behaviour. They were thoughtful and funny, expressing themselves with wisdom, with a sense of the world that is not attributed to children with disabilities positioned within dominant cultural discourses.

Their narratives ranged from feelings about themselves to feelings about major conflicts occurring in the world. For each child, the importance of those people and things in their lives that gave their life meaning was returned to over the course of our conversations. The importance of family, friends, animals, sport, play, art, music, dancing and reading gave a sense of belonging and an engagement with the world through which they could express their identities.

Reflections on the Children's Narratives

The children's narratives challenged the adult-centric view of age enabling emotional maturity, their narratives presenting an alterity that was often resilient and

concerned with the welfare of others. They cared for the world around them and others within their world. For example, Elliot's passionate statements on non-violence; Chontelle and Cheezel befriending children who were marginalised and alone; Ian Welsh, Brett and Max being concerned for the homeless; and Rambo's and Groovy Princess' protection of their parents. All the children displayed resilience and adaptability within their own lives, and care and concern for others. Their narratives presented alternative understandings to the dominant discourses on children with disabilities.

Within our conversations, the children spoke themselves into being through the stories they told of themselves and their lives. The children's perceptions of their identities were constructed through experiences of selfhood and sameness (Ricoeur, 1992); through awareness of their uniqueness and difference from other children, and through the dreams and desires for agency and belonging they share with others. They spoke of the insights they had into their own being, a being not always understood or respected by those around them. They understood themselves as being positioned as other by peers and adults, though this is not how they saw themselves. They knew their lived experience was different from their peers. Although this difference was often experienced as difficult, it was not always seen as lesser.

Children's desires for themselves and their lives spoke of purpose, transcendence and hope. Their desires to be who they chose to be and to live in ways that expressed their unique identities, and the meaning they found in their lives through their relationships with others and their world. I needed to closely consider the children's

stories of self as they reflected the shaping of their identities in an ongoing way, where being was enfolded in everyday relations.

Their expressions of identity were woven with their occupational engagement and, most importantly, were expressions where they did not position themselves within the family as children or siblings with disabilities. The children's narratives reflected those of children without disabilities (Brannen et al., 2000; Mayall, 1994, 1996). The children assumed responsibility for themselves and others. They negotiated and built relationships with all members of their family. They contributed to the family strength and growth (Dunst et al., 1994). These children responded to changes within the family, sometimes positively, sometimes negatively. They sought care and protection from their parents, and challenged their authority. They were actively involved in their family world and in creating a place of meaning within the home.

As occupational therapists, we need to engage with children as competent and valuable, helping to create opportunities that enable the enrichment of their lives and their position within their worlds of meaning. By doing this, we will be countering the current stereotypes of children with disabilities as passive and helpless (Davis & Watson, 2002). Within practice, it is important to position children as equal contributors to the decisions that affect their lives. If we build collaborative partnerships with children we can identify intervention strategies that are reflective and supportive of each child's identity (Law, 2002).

The heterogeneous nature of the children's family relationships (Davis & Watson, 2002) speaks of different rhythms of privacy and interaction within and across these relationships. As occupational therapists, we need to support children's active role

in their homeworlds. In order to enable children to engage in occupations (Canadian Association of Occupational Therapists, 1997) through which they can experience purpose, joy and agency, we must consider how our interventions will impact upon their engagement with others. How children relate to others, emotionally and physically, influences their level of participation in family work, leisure activities, self-care and the care of others, and ultimately their functional ability.

These considerations lead to the conclusion that it is necessary to consider the details of the ways in which individual children form relationships. We need to be sensitive to the vehicles children use to communicate, and the strategies they use with different people in their lives. In short, to build effective intervention strategies, it is essential that we understand the nuances of children's preferred means of communication and their position in personal and social landscapes.

The children in this study were "active creators of [their] social life rather than powerless products of society" (Williams & Bendelow, 1998, p. 20). They strongly situated themselves within their lifeworlds and the relationships that were important to them. They experienced and created senses of belonging within their family, within peer relationships, and with their much-loved pets; seeking to broaden and strengthen their belonging through acts of creative agency.

We need to be aware of children's desires for friends that interact with them as equals. All friendships include love and compassion for the other, but this is not based on perceiving the other as always vulnerable and in need of help. If we engineer children's friendships based on dependency, then we would be reinforcing the role of children with disabilities as lesser (Richardson, 2002; Shevlin et al., 2002). By enabling

friendships based on interdependency, we will be altering societal perceptions, reinforcing in children the value of their identities and challenging exclusion in all its forms (Gleeson, 1999). We will also enable the development of children's embodied spiritual qualities, which will contribute to their resilience in other contexts.

Many of the children actively dealt with the bullying of others in relation to their impairment. They sought to sustain a sense of agency and self-esteem within marginalising interactions with peers or adults. In these relationships they were positioned as lesser, as other. Their embodied selves were responded to with disconnection, from the other and from their lifeworld. These experiences challenged their connection with their selves as valuable and capable human beings. They often chose to respond to this positioning of marginalising otherness with creative strategies of resistance, whether through the use of absence, utilising the power of adults, verbally defending their position, or physically retaliating.

Positive school relations provided connections of love and trust when away from the safety of home and parental care, enabling the building of resilience through connection (Hunter, 2001). The negotiation of relations with others within the school setting is as important to the development of lifelong skills as children's functional skills. Relational skills enhance resilience and agency through choice, expression of the self, consciousness of others and the ability to negotiate conflict (Brown & Cohen, 1996). Being able to successfully negotiate the school world has implications for other contexts. Children can then carry these skills into the wider world with confidence.

Within the wider world, the children spoke of their engagement in other communities. In their neighbourhoods, they sought to build relationships, and

experienced isolation and rejection from others. Like many children without disabilities, they participated in sport, enjoyed family outings and went to church. Like many other children with disabilities, they were involved in medical and support services on a regular and on-going basis. Their involvement necessitated confronting difficult experiences, often without the respect and empathy of health professionals. However, the children's positioning of these experiences as an aspect of their lived experience, rather than a central focus, spoke of their greater engagement in other activities/aspects of their lives.

Within their narratives of world issues, there was a common humanness, a recognition of the self in the other and the other in the self, in their concerns for humanity. They were open to and compassionate towards difference in others, reflecting an ethical identity from the everyday to the global. Their desire for respect from others; from their parents to teachers, peers and health personnel, spoke of their desire to receive ethical consideration in their interactions with others.

From their understandings of self to their understandings of their lifeworlds these children wove their alterity of being. They actively negotiated their being in the world, through experiences of selfhood and sameness. Their resilience was supported through their ability to draw upon spiritual qualities and through the qualities offered to them by others. Their vulnerability was confronted through experiences of otherness, where their expressions of self were rejected or silenced. Each of the children identified how they experienced purpose, expressed their choices, and sustained and developed their sense of self. Through the uniqueness of their narratives they highlighted the heterogeneous nature of their lives, as children and as children with disabilities.

Limitations of the Study

The hermeneutic approach I chose to define spirituality and its embodiment has produced a particular interpretation of spirituality. Although this interpretation emerged following my immersion in and reflection on the literature, it remains my interpretation. Consequently, it may be incomplete, and is formed through the gaze of my professional and personal understandings.

I did not have personal access to a group of children with disabilities before ethics submission. Utilisation of a convenience sample of children without disabilities for the determination of topics and activities may have been injudicious. I may have commenced the interviews with different questions if this sample was a group of children with disabilities. However, the pilot interviews with Elvis and the multiple interviews with each participant meant each interview provided a learning experience for subsequent interviews.

I did not ask the children specifically about their understandings of the term 'spirituality'. This deliberate omission was made in order to retain the focus of the research on the lived experience of spiritual qualities. This focus entailed a deconstruction of the concept of spirituality, locating it in the everyday world. However, by not asking that particular question I do not know whether the children's responses may have led the research down a different path.

The gatekeeping by agencies may have precluded children from participating in the study. I did not have the 'power' to significantly influence the decision-making of agency staff, as noted in Chapter 4.

Of the 18 children who participated, only two had an acquired impairment. Although this factor will have influenced their life experiences and understandings of self, these children's narratives were not phenomenologically separable from those of the other children.

The voices of the 18 children reflected a diversity and richness of lived experiences. They represent a unique insight into the ways in which children with disabilities may draw upon spiritual qualities in their everyday lives. However, they cannot be seen as representative of the experiences of all children with disabilities, or all children with a particular impairment. The children's narratives need to be accepted as particular to their understandings at the moments in which we met.

As noted in Chapter 4, I was unable to approach all of the children for feedback on their summaries. Although I utilised strategies within conversations to clarify my understanding, I remain unaware of errors in my interpretation of their narratives and this will be reflected in the analysis.

In constructing the thesis, I privileged particular children's voices and particular narratives within those voices in thematic discussions. Thus, my interpretation of what was important to include, and what was able to be excluded, has produced a particular research gaze. This gaze has in turn produced a particular picture of the children's lives and their embodiment of spiritual qualities, which needs to be acknowledged.

Recommendations

Despite the limitations of the study, there are positive directions for further research. Privileging children's voices in our constructions of understanding their lives is an important area for occupational science. There needs to be an intertwining of

quantitative and qualitative research methodologies to enable children to have an active role in the decisions that affect their lives.

Inclusiveness must occur within the research context. In research with children, children need to participate in all aspects of the research process. By enabling inclusiveness, children will be respected as active and agentic participants. This thesis has highlighted the ability of children to contribute to the research process, from topic design to feedback on interpretations. To change the social and political landscape in which children currently sit there needs to be an expectation for occupational therapists to collaborate with children.

Longitudinal studies of children's lives are absent from the occupational therapy literature. Returning to the four children for feedback, 2 years later, and hearing stories of their current lives, impressed upon me the importance of knowing the paths their lives were taking. Witnessing the growth of children's identities and spirituality through longitudinal research will enable a deeper understanding of their needs. This understanding will promote more effective and reflective practice.

There needs to be further exploration of spirituality within the lives of children. The professional focus on spirituality as an enabling force within people's lives demands a development of the understanding of this force within children's lives. This thesis presents a beginning point for this understanding, a beginning that needs to be furthered with other children and explored in other contexts.

The influence of spirituality on children's experiences of resilience and vulnerability requires further investigation. Larger studies of children from differing life contexts will assist us in furthering our understanding of the importance of spirituality to

children's resilience and to the implications of spirituality within therapeutic interventions.

Further research is also necessary into specific issues identified by the children in this study. Children's experiences of family relationships, friendships and community experiences are under-researched within occupational therapy. There is a great need for us to understand children's viewpoints and desires, so that we tailor our interventions appropriately to meet their needs.

Investigating the contribution of spirituality in the lives of children without disabilities will enable us to consider the common threads and unique needs of all children. Although direct comparisons cannot be drawn across such qualitative research, there will be a deepening of our knowledge and appreciation of the lives of children as a larger group.

The contribution of occupational science research to occupational therapy practice entails a searching of other disciplinary knowledge to enhance our understanding (Yerxa, 2000). Within spirituality, this searching must explore bodies of knowledge beyond the medical, psychological and religious. Researching the lived experience of spirituality from other perspectives may initially challenge professional understandings, but ultimately will lead to professional growth.

Journeying

Where lies the land to which the ship would go?
Far, far ahead, is all her seamen know.
And where the land she travels from? Away,
Far, far behind, is all that they can say.

(Clough, 1968, p.104)

Within occupational therapy practice we see children for brief periods of their lives. We do not know the details of their personal histories, and how these histories have created their being. We do not know the longer term impacts of current issues in their lives, nor the outcomes of their choices, what they make of their becoming. We are like the seamen of the poem, joining their life journey for a time. Children must be respected as knowing themselves in the moments that we meet and we must listen to their stories.

For the children in this study, spirituality was embodied in all aspects of their lives. As an active and relational aspect of their identities, spirituality contributed to identity formation through qualities the children drew upon and those evoked in others. The embodiment of spiritual qualities impacted upon the children's experiences of vulnerability and resilience, influencing their engagement in occupational roles.

As reflective practitioners and researchers, we need to respond to children's narratives and ways of being in the world in order to maintain our own openness to difference and the ways in which we engage with children. Through a greater awareness of the lived experience of spirituality for children, we can help them to use their spiritual qualities in their engagement in life. For those children who are experiencing vulnerability, either across their life experiences or within particular contexts, we can

help them to draw upon their spirituality to promote resilience, enabling them to seek positive ways of being in the world.

This research contributes to the body of occupational science knowledge through the exploration of children's spirituality and its relation to the formation of identity. The exploration of the lived experience of spirituality and its implications for practice also contribute to the knowledge base of paediatric occupational therapy. These contributions enhance our understanding of children's lifeworlds and desires for themselves, positioning spirituality as a lived relation.

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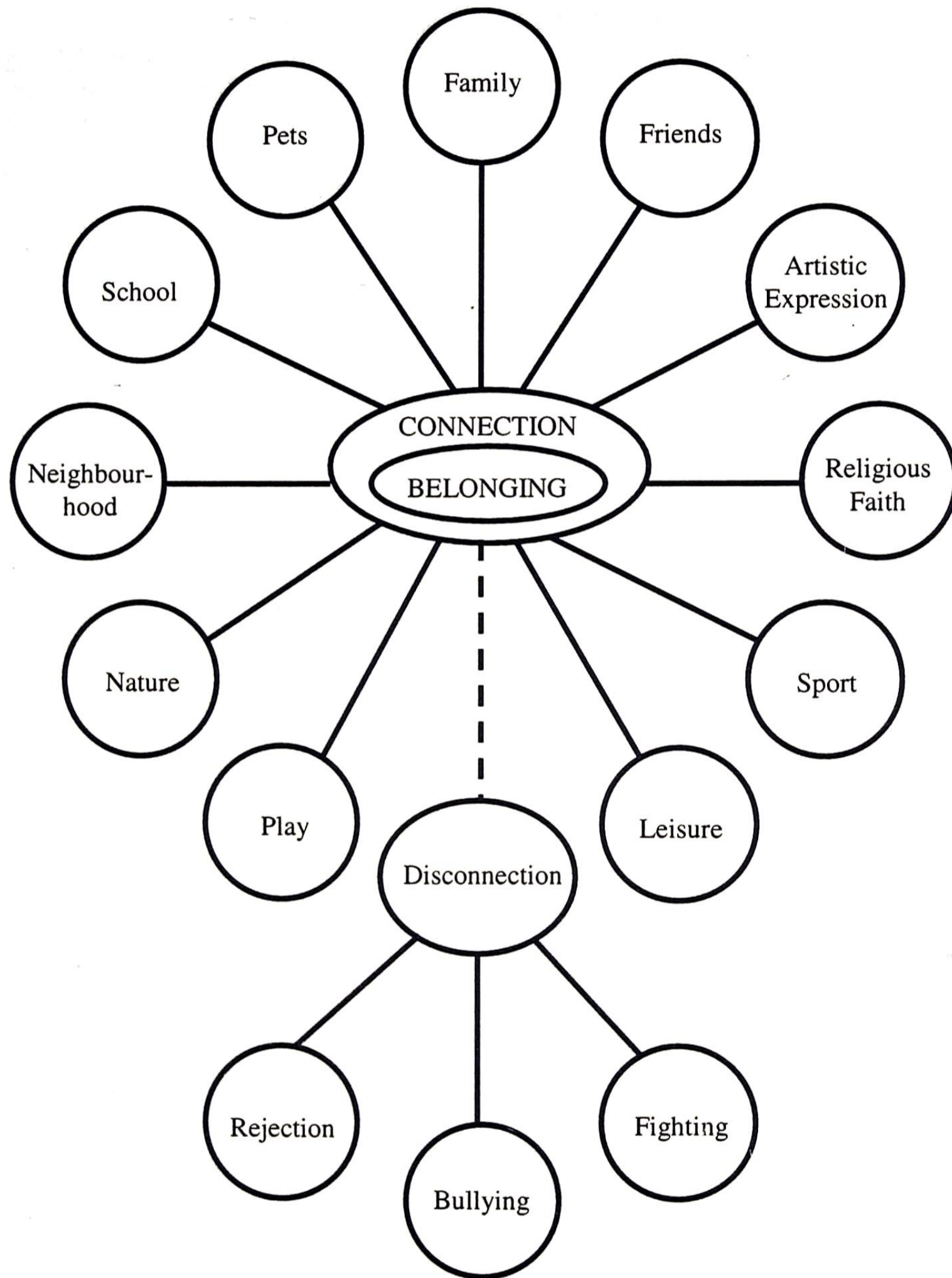
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Appendix A: Example of deductive method

Appendix B: Interview Topics

Interview Topics (GUIDE ONLY)

Initial Interview

Biographic Information

How old are you

When is your birthday

What name do you like to be called

Home

Who lives in your house

Do you have any pets

Do you have a favourite pet or toy

What chores do you do at home

Interests

What is your favourite music/groups

What sort of books do you like to read

What sort of movies/TV shows do you like

What are your favourite games

What are your favourite sports

Do you have a favourite toy

What is your most favourite thing to do

What would you like to know how to do

School

What grade are you in at school

What do you like most about school

What do you like least about school

What do you like learning about

Peers

Who is your best friend

What sorts of things do you like to do with him/her

Who are some of your other friends/kids you play with

Is there anyone at school that you don't like

Why don't you like him/her

Daily routine

Tell me about a regular day in your life (from when you get up to when you go to bed)

What are some of the special things that happen in your life

What are some of the things that happen in your life that you think don't happen in other kids lives

Perceptions of others

Have you ever heard of Jesus, Buddha, Superman, Britney Spears
What are 3 things you like about them

What are 3 things that make someone a good person
What are 3 things that make someone a bad person

What are 3 things you like, and 3 things you don't like, about (peer, sibling)

If you think about the best friend you could have in the whole world, what would they be like

Feelings

What are some ways to make someone happy
What are ways to make someone sad

If you have a fight with someone (eg. sibling, friend) -
What do you think about them
How do make everything ok again
If you feel really sad or angry what do you do to feel better

What makes the world a good place
What makes the world a bad place
What do you think the world should be like

Second Interview**Perceptions of self**

How are you like other kids
How are you different to other kids
When you daydream, what do you dream about

Who matters to you/Who do you care about
What matters to you
What do you believe in

What makes you happy
What makes you unhappy
What makes you feel strong inside
What makes you feel scared inside
Tell me about a really happy time in your life

Third Interview**Present**

See yourself at the age you are now, living your life in exactly the way you want. What are you doing, How do you feel

Future

Imagine what it will be like when you're grown up. How do you feel, What are you doing, What's the world like

Wishes

What are 3 wishes you would like to have come true

Perceptions of embodiment of qualities

Can you tell me a story about –

Hope

Courage

Trust

Joy

(story from your own life, or a story you have heard)

Appendix C: Approval Letter



COPY

HUMAN ETHICS COMMITTEE

The University of Sydney
Room K4.01 Main Quad A14
Sydney 2006

Tel: (02) 9351.4474 Fax: (02) 9351.4812 E-mail: human.ethics@reschois.usyd.edu.au

Ms R Beltran
School of Occupation and Leisure Sciences
C42

08 August 2001

Dear Ms Beltran

Title: *being and Becoming: spirituality in the lives of children with disabilities*

Ref No: 01/06/08

I am pleased to inform you that the Human Ethics Committee at its meeting on 25/06/01 approved your protocol on the above study. Please note that subject to annual monitoring returns, the approved protocol is valid for five years.

In order to comply with the *National Statement on Ethical Conduct in Research Involving Humans*, and in line with the Human Ethics Committee requirements the Chief Investigator's responsibility is to ensure that:

- (1) The individual researcher's protocol complies with the final and Committee approved protocol.
- (2) Modifications to the protocol cannot proceed until such approval is obtained in writing.
- (3) The confidentiality and anonymity of all research subjects is maintained at all times, except as required by law.
- (4) All research subjects are provided with a Subject Information Sheet and Consent Form.
- (5) The Subject Information Sheet and Consent Form be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers.
- (6) The following statement appears on the bottom of the Subject Information Sheet:
Any person with concerns or complaints about the conduct of a research study can contact the Manager of Ethics and Biosafety Administration, University of Sydney, on (02) 9351 4811.
- (7) The standard University policy concerning storage of data and tapes should be followed. While temporary storage of data or tapes at the researcher's home or an off-campus site is acceptable during the active transcription phase of the project, permanent storage should be at a secure, University controlled site for a minimum of five years.
- (8) A progress report is provided by the end of each year. Failure to do so will lead to withdrawal of the approval of the research protocol and re-application to the Committee must occur before recommencing.
- (9) A report and a copy of the published material is provided at the end of the project.

Yours sincerely

Professor Jeff Sigafos
Chairman
Human Ethics Committee

cc. Ms I Burgman, School of Occupation and Leisure Sciences C42,

Appendix D: Agency Approvals



the spastic centre

Ms Imelda Burgman
School of Occupation & Leisure Sciences
University of Sydney
Cumberland Campus
PO Box 170
Lidcombe NSW 2141

3rd December 2001

Dear Imelda,

I acknowledge receipt of your letter dated 27th November 2001, addressing the need to modify the Parent Information Sheet in your project ***Being and Becoming***, as requested by The Spastic Centre's Ethics Committee. Given this modification, The Ethics Committee now gives approval for this project to commence as outlined in your original Ethics Application.

The Ethics Committee wishes you well with the project and would like to hear the results of your project on completion. On completion, a copy of your research paper should be sent to me so that it can be catalogued in our library for future reference.

Yours sincerely,

Amanda Buzio
Professional Development Advisor
Secretary Ethics Committee



Renwick College

Affiliated with the University of Newcastle,
Administered by the Royal Institute for
Deaf and Blind Children

Campus: 361-365 North Rocks Road
North Rocks NSW 2151

Postal Address: Private Bag 29
Parramatta NSW 2124 Australia

Telephone: (02) 9872 0303 (Voice/TTY)
Facsimile: (02) 9873 1614
e-mail: renwickenq@ridbc.org.au

21 December 2001

Ms I Burgman
School of Occupation & Leisure Sciences
University of Sydney
P O Box 170
LIDCOMBE 1825

Dear Ms Burgman,

Thank you for your application to undertake research with teachers and students at the Royal Institute for Deaf and Blind Children. The Educational Research Advisory Committee considered your application on 14th November 2001. I am pleased to inform you that the committee granted approval for you to approach teachers and families participating in services provided by the Institute. As your study will focus upon children with a range of disabilities, please contact Yvonne Ong on 9872 0373 to obtain contact details for Heads of Department across the Institute.

Please note that the number of children meeting your criteria will likely to be small and the committee would strongly encourage you to work with the Department of Education and Training where potential numbers of participants are likely to be much higher.

Yours sincerely,

Dianne Toe
Chair
Educational Services Research Advisory Committee



Royal Institute for
Deaf and Blind Children

Patron:
Her Excellency
Prof. Marie Bashir AC
Governor of NSW



THE NORTHCOTT SOCIETY

Established in 1929 as The NSW Society for Crippled Children

ACN 000 022 971

ABN 87 302 064 152

11 March 2002

Imelda Burgman
School of Occupation & Leisure Sciences
The University of Sydney
Cumberland Campus C42
PO Box 170
Lidcombe NSW 2141

Dear Imelda

Following our discussions and your presentation at our team meeting we are able to participate in your research project "Being and Becoming".

We are able to advertise the project in our newsletter which goes out to all families involved with the school age, Family Support Service.

As you would be aware we are unable to give out personal details of families without their informed consent and without their expressions of interest in the "Being and Becoming" project.

Alongside advertising the project, the workers will endeavour to discuss the project with families who might be interested. Through this we can pass on the information you have provided about the project so that families can make an informed choice about their involvement.

Please contact me on 9890 0162 if you have any further questions.

Yours sincerely

Louise McVay
Coordinator, Family Support Program

NORTHCOTT - People Helping People with Disabilities.

The Northcott Centre, 2 Grose Street, North Parramatta, NSW 2151 PO Box 4055, Parramatta, NSW 2124 Tel. (02) 9890 0100 Fax (02) 9683 2827
Internet Address: <http://www.northcott.com.au> Email: nc@northcott.com.au



SOUTH EAST HEALTH
South Eastern Sydney Area Health Service

RESEARCH ETHICS COMMITTEE - Eastern Section

Room G71, EBB
Cnr High & Avoca Strs
RANDWICK NSW 2031
Tel: 9382 3587
Fax: 9382 2813

28th August 2002

Ms Ruth Beltran
School of Occupation and Leisure Sciences
University of Sydney
PO Box 170
LIDCOMBE NSW 1825

Dear Ms Beltran

Re: Being and Becoming: Spirituality in the Lives of Children with Disabilities.
REF: 02/104

The Research Ethics Committee at its meeting of 27th August 2002 considered the Executive Approval given on 10 July 2002 for the following for the above study, and this decision was ratified.

- **Provision of the Signature of Scientific Merit.**
- **Parental Consent Form.**
- **Child's Consent Form.**

In accordance with the National Health and Medical Research Council Guidelines, the Committee requires you to furnish it with a progress report every 12 months until and on completion of the study.

The Committee wish you well with the continuation of your study.

Yours sincerely

Kim Breheny
Executive Officer
Human Research Ethics Committee - Eastern Section



Royal Blind Society
a vision to share

Imelda Burgman
School of Occupation and Leisure Sciences
University of Sydney
Faculty of Health Sciences
Cumberland Campus
PO Box 170
Lidcombe NSW 1825

Dear Imelda

Further to your request to include clients of Royal Blind Society in your research I am writing to inform you that we are happy to:

- advertise your research project in our Update newsletter
- have you conduct a presentation to our school aged team
- mail out research information and an invitation to participate to clients who have been identified by this team

Best of luck with your research and we will be interested to read the final report.

Yours sincerely

Helen Lunn

Helen Lunn
Manager
Child and Family Services

Appendix E: Agency Letter



The University of Sydney

School of Occupation and Leisure Sciences
Faculty of Health Sciences
College of Health Sciences

Cumberland Campus C42
East Street (PO Box 170)
Lidcombe NSW 2141
Telephone: +61 2 9351 9181
Facsimile: +61 2 9351 9196

Dear

I would like to request your assistance to provide parents with the attached letter of invitation, and parent and child information sheets, in relation to my qualitative research project:

BEING & BECOMING

I have been a paediatric occupational therapist for the past 20 years and I am currently undertaking Doctoral studies. I believe that it is important for occupational therapists to further understand what children with disabilities think and feel about their lives, what matters to them, and how they make choices about how they engage in life. I believe that this understanding will help occupational therapists to more effectively assist children with disabilities in ways that are meaningful for the children, thereby fostering their engagement in life, with all its challenges.

I am interested in interviewing 20-30 children who are between 8 years and 11 years old. They can have any kind of disability as I am interested in talking with children who have different disabilities to see if there are common feelings or differences. The main criterion is that the parent feels that his/her child will be interested and able to respond to the interview process. If you know of parents who may be interested but who have difficulties with written English, I am very happy to meet with them to go through the forms. I am contacting a selection of agencies/organisations with my request for participants.

Please feel free to read the parent and child information for further detail. If you have any further questions before distributing the information, please contact me at the School of Occupation & Leisure Sciences on:
02 93519181

Thank you for your assistance.

Yours faithfully,

Imelda Burgman MA OTR BCP
Occupational Therapist (AccOT)

Appendix F: Letter of Invitation**The University of Sydney****School of Occupation and Leisure Sciences**Faculty of Health Sciences
College of Health SciencesCumberland Campus C42
East Street (PO Box 170)
Lidcombe NSW 2141
Telephone: +61 2 9351 9181
Facsimile: +61 2 9351 9196**LETTER OF INVITATION**

Dear Parent,

Please find attached, information for you and your child regarding the research I wish to undertake. If after reading the enclosed information you and your child think that he/she may like to participate, could you please fill in the section below, place it in the envelope provided, and return it to me by / /2001.

When I receive your reply I will telephone you to make a time to meet with you and your child to talk about the research in more detail.

Thank you for your consideration and interest.

Yours faithfully,

IMELDA BURGMAN

My child is interested in being contacted regarding the research project –
BEING & BECOMING

NAME: _____

ADDRESS: _____

TELEPHONE: _____

Most convenient time of day/days to call:

Appendix G: Parent Information



The University of Sydney

School of Occupation and Leisure Sciences

Faculty of Health Sciences
 College of Health Sciences
 Cumberland Campus C42
 East Street (PO Box 170)
 Lidcombe NSW 2141
 Telephone: +61 2 9351 9181
 Facsimile: +61 2 9351 9196
 Email: i.burgman@cchs.usyd.edu.au

PARENT INFORMATION

Title of project: **Being & Becoming**

I would like to invite your child to participate in my research study **Being & Becoming**. The purpose of this research is to understand how children with disabilities experience meaning and purpose in their lives by asking them about what matters to them and how they deal with the world. This study is being conducted to meet the requirements for the degree of Doctor of Philosophy under the supervision of Ruth Beltran (phone: 02- 93519295) of the School of Occupation & Leisure Sciences. I have been a children's occupational therapist for the past 20 years.

I would like to interview your child over 3-5 sessions (up to an hour each time) at a place and time convenient to you. This will allow me to develop a relationship with your child, so that he/she will feel comfortable in talking with me about what matters to him/her. I would like to audiotape these sessions, so that I don't forget anything that your child has shared. I would like to also use art materials to help your child to feel comfortable, such as drawing. In addition, I would like to discuss with you whether you would feel comfortable with your child taking photos of important people, places and things in his/her life, so that we can talk about them during our sessions together. I am willing to provide a disposable camera for your child to use, and to pay for the development of the photos. I am very happy to make the questions I intend to ask available to you, and to discuss whether you feel they need to be altered in any way to suit your child.

It is anticipated that these interviews will take place between September, 2001 and December, 2002. The time and location of the interviews will be made at your and your child's convenience, for example, at your home in an after school time. I would like to do a follow-up interview with your child after I have spent time writing up what he/she has said over the course of the interviews. This will help me to be sure that I have understood him/her correctly, so that I will not be misrepresenting his/her thoughts and feelings. If your child wishes to read any of the information collected about him/her, he/she will be free to do so. On completion of the research each child and his/her parent will be sent a copy of the summary, and you will be welcome to read the final document.

Whether or not you are also present at the interviews, or whether you are more comfortable just being nearby, is the choice of you and your child. The purpose of this research is to find out what children think and feel. I will not be attempting to influence your child's thinking in any way. If your child discloses any information of concern during an interview I will inform you immediately. All information shared by your child will remain confidential, except as required by law.

I cannot and do not guarantee or promise that your child will receive any benefits from this study.

Any information that is obtained in connection with this study and that can be identified with you or your child will remain confidential and will be disclosed only with your permission. If you give me your permission I plan to make the information from this research available to occupational therapists through written papers and presentations. It will hopefully help occupational therapists to better understand what children think and feel, and how to more effectively assist them in doing what they

wish to do and in becoming who they wish to be. In any publication or presentation, information will be presented in such a way that you or your child will not be able to be identified.

Your decision whether or not to permit your child to participate will not prejudice or impact you or your child's future relations with the University of Sydney or the service provider. If you decide to permit your child to participate, you are free to withdraw your consent and to discontinue your child's participation at any time without prejudice.

If you have any concerns, or further questions, you can contact me at the University of Sydney, on:
(02) 93519181

Or my supervisor, Ruth Beltran, at the University of Sydney, on:
(02) 93519295

Please keep this information sheet.

Yours faithfully,

Imelda Burgman MA OTR BCP
Occupational Therapist AccOT

**If you have any concerns or complaints about the conduct of this research please contact,
Manager for Ethics and Biosafety Administration, University of Sydney, on
(02) 93514811**

Appendix H: Kids Information



The University of Sydney

School of Occupation and Leisure Sciences

Faculty of Health Sciences
College of Health Sciences

Cumberland Campus C42
East Street (PO Box 170)
Lidcombe NSW 2141
Telephone: +61 2 9351 9181
Facsimile: +61 2 9351 9197

KIDS INFORMATION

Project title: Being & Becoming

I would like you to help me find out what kids with disabilities think; about who they are and what really matters to them. I am studying at The University of Sydney and have been a kids' occupational therapist for a long time. I think it's really important for occupational therapists to understand what kids think so that we can help them do what they want to do and be who they want to be.

If you would like to help me, I would like to see you at least 3 times and maybe up to 5 times, for about an hour each time. We can get to know each other and you will have enough time to say everything you want to say. I would like to use a tape recorder to record our talks (I'm a very slow writer). You can turn the tape recorder off whenever you feel like it. There are no wrong topics or answers while we talk, I would just like to know how you think and feel about different things in your life. Everything you say will be confidential, except as required by law.

I will also bring drawing materials and other activities with me in case you'd like to do something while we are talking. I will also bring a disposable camera so that you can take photos between our talks of special people, places and things in your life, if you wish.

It's ok if you decide during our talks that you want to stop. It's also ok if you don't want to continue with our talks, just tell me or get mum or dad to let me know. When we finish our talks I would like to check what I have written with you to make sure that I have got it right. I will not be using your real name, you can choose what you wish to be called.

I will be talking with a lot of kids and will be putting all the information together for other people to read. When I have finished, I will send you a summary of what I have written and you can read the whole thing if you want to.

Other occupational therapists will read the final paper, hopefully it will help them to better understand what children think and feel, and how to help them do what they want to do and be who they want to be.

If you have any questions, please phone me, or ask mum or dad to phone me on:
(02) 93519181

Please keep this information sheet.

Imelda Burgman

If you have any concerns or complaints about the conduct of this research please contact, Manager for Ethics and Biosafety Administration, University of Sydney, on (02) 93514811

Appendix I: Modified Letter of Invitation & Parent Information



The University of Sydney

School of Occupation and Leisure Sciences

Faculty of Health Sciences
College of Health Sciences
Cumberland Campus C42
East Street (PO Box 170)
Lidcombe NSW 2141
Telephone: +61 2 9351 9181
Facsimile: +61 2 9351 9196

INVITATION

Dear Parent,

I want to ask your son/daughter to be part of my study. Please read the information in this envelope. If you are interested, please fill in the bottom part of this letter and send it to me. I will phone you to make a time to visit you.

Thank you.

Yours faithfully,

IMELDA BURGMAN

BEING & BECOMING

NAME:

ADDRESS:

TELEPHONE:

Best time to phone:



The University of Sydney

School of Occupation and Leisure Science

Faculty of Health Sciences
 College of Health Sciences
 Cumberland Campus C42
 East Street (PO Box 170)
 Lidcombe NSW 2141
 Telephone: +61 2 9351 9181
 Facsimile: +61 2 9351 9196
 Email: i.burgman@fhs.usyd.edu.a

PARENT INFORMATION

Title of project: Being & Becoming

I want to ask your child to be part of my study. This study is to find out how children with disabilities feel about themselves, what is special to them and what they think about the world. This study is being done for a Doctor of Philosophy under the supervision of Ruth Beltran, at the School of Occupation & Leisure Sciences.

I would like to see your child 3-5 times (for an hour each time) at a place and time that suits you. This will help me to get to know your child, so that he/she will feel ok about talking to me. I would like to use a tape recorder so that I don't forget what your child has said. Also, I would like to ask you whether it is all right with you for your child to take photos of people, places and things in his/her life, so that we can talk about them. I will give your child a camera to use, and I will pay for the photos. I am very happy to show you the questions I will ask.

I will come and see your child when it is easiest for you, for example, at your house after school. I would like to talk to your child again after I have written about what he/she has said to me. This will help me to be sure that I have understood him/her. Your child can read anything I write about him/her. I will send you and your child a copy of the summary, and you will be welcome to read the final report.

Whether or not you want to be in the room with us is up to you and your child. This research is to find out what children think and feel. I will not try to make your child think in any special way. If your child tells me anything that may worry you while we are talking, I will let you know. Everything your child says will be private, except as required by law. I can't and don't promise that your child will get anything special from this study.

I do want other occupational therapists to be able to read and hear about this study. It will help occupational therapists to understand what children think and feel, and how to help them do what they want to do and to be the person they want to be. I will make sure that nobody will know who you are, or who your child is.

Whether or not you let your child talk with me will not make a difference to how the University of Sydney or the Spastic Centre of NSW treats you or your child. If you let your child talk with me, you can still change your mind at any time and ask me not to come back.

If you want to ask me anything, you can phone me at the University of Sydney, on:
(02) 93519181

Or phone my supervisor, Ruth Beltran, at the University of Sydney, on:
(02) 93519295

Please keep this information.

Yours faithfully,

Imelda Burgman MA OTR BCP
Occupational Therapist AccOT

If you have any concerns or complaints about the conduct of this research please contact, Manager for Ethics and Biosafety Administration, University of Sydney, on (02) 93514811

Appendix J: Parent Consent Form



The University of Sydney

School of Occupation and Leisure Sciences

Faculty of Health Sciences
College of Health Sciences

Cumberland Campus C42
East Street (PO Box 170)
Lidcombe NSW 2141
Telephone: +61 2 9351 9181
Facsimile: +61 2 9351 9196

PARENTAL (OR GUARDIAN) CONSENT FORM

1. I, _____ of _____, agree to permit _____, who is aged _____ years, to participate as a subject in the research project described in the Parental Information Statement attached.
2. I acknowledge that I have read the Information Statement, which explains the aims of the research and the nature and possible risks of the interviews, and the statement has been explained to me to my satisfaction.
3. Before signing this Consent Form, I have been given the opportunity of asking any questions relating to any possible physical or mental harm my child might suffer as a result of participation and I have received satisfactory answers.
4. I understand that I can withdraw my child from the study at any time without prejudice to my or my child's relationship to the University.
5. I agree that research data gathered from the results of the study may be published provided that neither my child nor I can be identified.
6. I understand that all information given to the researcher by my child shall remain confidential except as where required by law.
7. I understand that if I have any questions relating to my child's participation in this research, I may contact _____ on telephone _____, who will be happy to answer them.
8. I acknowledge receipt of a copy of this Consent Form and the Information Statement

Signature of Parent/Guardian

Signature of Witness

Please PRINT Name

Please PRINT Name

Date

Nature of Witness

Signature of Investigator

Please PRINT Name

Page 1 of 1

Appendix K: Child's Consent Form



The University of Sydney

School of Occupation and Leisure Sciences

Faculty of Health Sciences
College of Health Sciences

Cumberland Campus C42
East Street (PO Box 170)
Lidcombe NSW 2141
Telephone: +61 2 9351 9181
Facsimile: +61 2 9351 9196

CHILD'S CONSENT FORM

1. I, _____, of _____, hereby consent to my involvement in the research project titled "Being & Becoming".
2. I acknowledge that the nature, purpose and the contemplated effects of the research so far as it effects me have been explained to my satisfaction by the researcher and my consent is given voluntarily.
3. The details of the research interviews have been explained to me, including the anticipated length of time required and the frequency of the interviews.
4. I am aware that, although the purpose of this research is to improve the quality of intervention for children with disabilities, it may not result in any direct benefit to me.
5. I have been given the opportunity to have a member of my family or adult friend present while the research was explained to me.
6. I have been informed that no information will be published so as to reveal my identity.
7. I understand that all information will remain confidential except as where required by law.
8. I give permission for the above researcher to audiotape the interviews, to collect drawings, and to develop photographs.
9. I understand that the drawings and photographs will be returned to me at the completion of the researcher's thesis.
10. I have been informed that the audiotapes and other written materials will be kept in secure storage for 5 years as required by the University, after which they will be destroyed.
11. I understand that I am free to withdraw from this research at any stage without prejudice to my or my parents relationship to the University.
12. I understand that if I have any questions relating to my participation in this research, I may contact, or ask an adult to contact, _____ on _____, who will be happy to answer them.

Signature of child

Signature of Witness

Please PRINT Name

Please PRINT Name

Date

Nature of Witness

Signature of Investigator

Please PRINT Name

Appendix L: Consent Form - Use of Visual Media



The University of Sydney

School of Occupation and Leisure Sciences
Faculty of Health Sciences
College of Health Sciences

Cumberland Campus C42
East Street (PO Box 170)
Lidcombe NSW 2141
Telephone: +61 2 9351 9181
Facsimile: +61 2 9351 9196

CONSENT FORM

- USE OF VISUAL MEDIA -

I,, of
hereby give my consent to the use of my drawings/art work/photographs in the
written work and presentations by Imelda Burgman in specific relation to her
research on **Being & Becoming**, as detailed below:

Itemised list of visual media:

-
-
-
-
-
-
-
-
-
-

Signature of child

Signature of Witness

Please PRINT Name

Please PRINT Name

Date

Nature of Witness

Signature of Investigator

Please PRINT Name

Appendix M: Participants

Pseudonym	Gender	Age (years)	Main Impairment	Home Context	School Context	Community Context
Elvis	Male	8	Physical	Mother, father 4 siblings	Public	Urban
Ian Welsh	Male	9	Visual	Mother, father 2 siblings	Public	Urban
Cheezel	Male	9	Hearing	Mother, father 4 siblings	Public	Urban
Chontelle	Female	10	Hearing	Mother 1 sibling	Specialised + Catholic	Urban
Cerberus	Male	8	Physical	Mother, father 2 siblings	Catholic	Rural
Max	Male	10	Hearing	Mother, father 2 siblings	Private	Urban
Lisa	Female	9	Visual	Mother, father 2 siblings	Public	Urban
Deatherford	Male	10	Behavioural	Mother, father 1 sibling	Public	Urban
Brett	Male	11	Visual	Father 1 sibling	Catholic	Country
Elliot	Male	10	Visual	Father, father's partner	Christian	Urban
Bobby	Male	9	Visual	Mother, stepfather 2 siblings	public	Urban
SSS007	Male	10	Physical	Mother, father 1 sibling	Christian	Rural

Pseudonym	Gender	Age (years)	Main Impairment	Home Context	School Context	Community Context
Rambo	Male	10	Physical	Mother 2 siblings	Public	Urban
Michael Jackson	Male	10	Physical	Mother, father 2 siblings	Special Education Unit	Urban
Barney	Female	9	Physical	Mother, father 1 sibling	Special Education Unit	Urban
Nina	Female	10	Learning	Mother, father 2 siblings	Public	Urban
Groovy Princess	Female	10	Physical	Mother, father 3 siblings	Public	Rural
Keeta	Female	8	Physical	Mother 1 sibling	Public	Rural

Appendix N: Information Statement (Photographs)



The University of Sydney

School of Occupation and Leisure Sciences

Faculty of Health Sciences
College of Health Sciences

Cumberland Campus C42
East Street (PO Box 170)
Lidcombe NSW 2141
Telephone: +61 2 9351 9181
Facsimile: +61 2 9351 9197

INFORMATION STATEMENT (PHOTOGRAPHS)

_____ (child's name) would like permission to take your photo as part of his/her involvement in a research project, entitled

Being & Becoming

The aim of the research project is to understand what kids with disabilities think about who they are and what really matters to them. This study is being conducted to meet the requirements for the degree of Doctor of Philosophy under the supervision of Ruth Beltran (phone:02-93519295) of the School of Occupation & Leisure Sciences.

_____ (child's name) is taking photos of people, places and things that are important to him/her. These photographs will only be used in discussions with the student researcher, Imelda Burgman, who is conducting this project. The photos will help Imelda to know about _____ (child's name) world without intruding upon it.

I cannot and do not guarantee or promise that you will receive any benefits from this study.

Any photographs taken will remain the sole property of _____ (child's name) and will not be published.

If you have any concerns, or further questions, you can contact me at the University of Sydney, on:
02-93519181

Please keep this information sheet.

Yours faithfully,

Imelda Burgman MA AccOT OTR BCP
Occupational Therapist

If you have any concerns or complaints about the conduct of this research please contact, Manager for Ethics and Biosafety Administration, University of Sydney, on (02) 93514811

Appendix O: Photograph Consent Form

PHOTOGRAPH CONSENT FORM

1. I, _____ of

agree to permit
_____, to take my photograph as part of
his/her involvement in the research project "Being & Becoming".
2. I acknowledge that I have read the Information Statement, which explains the aims of the research and the nature of the use of the photographs.
3. I understand that my photograph will remain confidential between the student researcher and the above named child, except as required by law.
4. I understand that if I have any questions in relation to my photograph and its use, I may contact Imelda Burgman on telephone 93519181, who will be happy to answer them.

Signature of person

Signature of witness

Please PRINT Name

Please PRINT Name

Date

Date

Appendix P: Certificate of Appreciation

Certificate of Appreciation

Presented to:

for participating in the PhD research project

BEING & BECOMING

In 2002

Imelda Burgman, Occupational Therapist

Appendix Q: Theme Identification

Home

Who lives in your house? Pets? Toys?

→Family, pets, sense of place

→Relationships, connection, meaning

→Belonging, love, purpose, compassion

Chores?

→Responsibility, agency, self esteem, contribution to family life

→Purpose, consciousness

Interests

Music? Books? Movies? TV shows? Games? Sports? Toys?

→Meaning, happiness, creativity, connection, flow, curiosity

→Purpose, joy, transcendence, belonging, wonder

What is your most favourite thing to do?

→Meaning, happiness, connection, flow

→Purpose, joy, belonging, creativity

What would you like to know how to do?

→Meaning, happiness, wishes, desires, empowerment, curiosity

→Purpose, joy, hope, creativity, transcendence

School

What do you like most/least about school?

→Meaning, connection, happiness, awareness

→Purpose, belonging, joy, consciousness

What do you like learning about?

→ Meaning, flow, curiosity, agency

→ Purpose, joy, creativity

Peers

Best friend? Other friends?

→ Relationships, qualities, connection, otherness

→ Belonging, love, joy, compassion, consciousness, ethics, trust

Play and leisure pursuits with friends?

→ Meaning, connection, flow, agency

→ Purpose, belonging, creativity, joy

Is there anyone at school you don't like? Why?

→ Connection, qualities

→ Belonging, consciousness, ethics, trust, faith

Daily Routine

What are some of the special things that happen in your life?

→ Meaning, pleasure, connection

→ Purpose, joy, belonging, transcendence

What are some of the things that happen in your life that you think don't happen in other kids lives?

→ Meaning, challenges, alterity

→ Purpose, consciousness, courage

Perceptions of Others

Have you ever heard of Jesus, Buddha, Superman, Britney Spears?

What are 3 things you like about them?

→Qualities, meaning, omnipotence, agency, awareness

→Transcendence, purpose, consciousness

What are 3 things that make someone a good person/ bad person?

→Qualities, morality, connection, awareness

→Ethics, belonging, consciousness

What are 3 things you like, and 3 things you don't like about (friend or sibling)

→Awareness, morality, connection

→Consciousness, ethics, belonging

If you think about the best friend you could have in the whole world, what would they be like?

→Qualities, connection

→Ethics, love, belonging

Feelings

What are some ways to make someone happy?

→Awareness, happiness

→Consciousness, compassion, joy, love

What are ways to make someone sad?

→Awareness, morality

→Consciousness, compassion, ethics

If you have a fight with someone -

What do you think about them?

→Agency, morality, connection, justice, awareness

→Faith, ethics, belonging, consciousness, wisdom, compassion, courage

How do you make everything ok again?

→Agency, morality, connection, justice

→Compassion, wisdom, belonging, ethics

If you feel really sad or angry, what do you do to feel better?

→Agency, justice

→Faith, ethics, hope, transcendence

What makes the world a good place/bad place?

→Connection, awareness, humanity, meaning, morality

→Belonging, consciousness, love, purpose, compassion, ethics

What do you think the world should be like?

→Humanity, awareness, justice, wishes, meaning

→Belonging, consciousness, hope, ethics, purpose, compassion

Perceptions of Self

How are you the same and different to other kids?

→Uniqueness, alterity, connection, qualities, awareness, otherness

→Belonging, consciousness, wisdom

When you daydream, what do you dream about?

→Wishes, dreams, meaning, alterity

→Hope, faith, transcendence, purpose

What makes you happy/unhappy?

Tell me about a really happy time in your life?

→Agency, happiness, sadness, anger, flow, meaning

→ Purpose, joy, creativity, transcendence, grace, compassion, consciousness

What makes you feel strong/scared inside?

→ Agency, meaning, fear, brave

→ Purpose, courage, faith, hope, trust

Present

If you could live your life exactly the way you want, what would you do? How would you feel?

OR If you could change anything about your life, what would it be?

→ Meaning, awareness

→ purpose, consciousness, hope, transcendence

Future

Imagine what it will be like when you grow up. What are you doing? What's the world like?

→ Agency, meaning, awareness, desires, dreams, connection

→ Purpose, faith, hope, consciousness, belonging

Wishes

What are 3 wishes you would like to have come true?

→ Meaning, awareness, desires, dreams

→ Purpose, consciousness, hope, transcendence

Appendix R: Lisa - Summary

Creativity

As for many of the other children, Lisa simply stated, "Yeah, I like drawing." (1/2). She was especially interested in the names of the colours of the drawing materials I had brought and in identifying and describing the differences between similar colours. Her interest in colour resonated with Ian Welsh's, both children with visual impairments. Perhaps their interest stemmed from their visual difficulties, becoming more visually sensitive to colour, where colour was providing a richer way of 'identifying' and understanding their visual world, a means of deeper connection.

Lisa's first drawing was of her horse, that she had had and loved when she was younger. Like some of the other children she denigrated her drawing ability by saying, "I'm not good at drawing horses... Not good at horses. Looks like a leopard." (1/9). She initially drew her horse standing in a green field, leaning forward with a sense of imminent movement, and then chose to include herself riding her. Drawing herself as an outline (a ghostly figure) sitting astride her on a saddle holding the reins with one hand, with a smile on her face. Perhaps placing herself as an outline, not quite real, connected with her knowing that this was something she could only do within her imagination.

Lisa's drawing of 'Tigers and Water Fountain' came from her love of animals. While she was drawing and amongst our conversation, she spoke directly into the tape recorder, "Hello, what's your name, my name's [Lisa] and I'm drawing um a a a zoo well it's not actually a zoo, just a tiger's cage, soon I'll be up to the tiger, but for now I'm doing the um the water fountain. It will look nice, it will! even though if you don't

have eyes I'm really sorry, even though if you can't hear me I'm really sorry too. All right, hello. My name's [Lisa]!"(1/36). An animated dialogue with the world of readers of my thesis, proud and confident. She decided to add algae to the rocks in her tiger cage, "You know that green stuff that you find on beaches on rocks? Well that's, that's what I'm going to do on this. That's what I'm going to do on the rocks, some rocks so the tiger doesn't step on these, cause I have a little um gate around here. Yeah around, mm. Cause the zoo comes along and wipes the algae off but they haven't done it in a week so its grown back. I won't do it on that rock."(1/41). Connecting with her experiences at the beach and keeping her tigers safe from harm, as she likes to be. Lisa finished this drawing between our first and second conversation. It was a detailed drawing full of the liveliness and beauty of tigers. Each of the nine tigers had an individual pose; whether crouching, lying in the sun, standing alert, tails up or down, walking, and all were smiling their tiger smile.

Lisa's joy in artistic creative expression, "[I like] Drawing, making things. And Playdoh."(2/30) and animals was evident in her drawings, in the pipe cleaner figure that she made of a horse, in the mobiles that she showed me of a dog and a cat, "I made that cause I used to go to art class."(2/13). Her intense involvement in what she created when we were together, the colours, shapes and feel of her work. She took pleasure in taking photos of her artwork, both in the use of the camera and in the recording of her creativity. The pipe cleaner horse became the 'Star' of her storybooks and then she chose to draw a picture of 'Star', "That's Star that's running."(2/26) with her model sitting beside her drawing paper, "Star can watch me draw."(2/24) embodiments of

'Star' filling her immediate world. Her picture of 'Star', "...she's running in long grass."(2/37) was of a graceful, very feline, and ethereal horse, who appeared to be dancing over the long grass with her long black tail streaming behind her. Lisa spoke into the tape recorder again, "So hello, what's your name, do you like my picture of grass? Oh yes I do, oh yes oh yes."(2/37).

Agency

Lisa was in grade 3 at school, which she explained this way, "I'm in Year 3, be I would have been in Year 4 if I didn't repeat, I'm bad at maths, well I'm, I don't know. Um, I'm not good at maths. *Yeah? Just really, really hard?* Mm, very hard for me."(1/3). She had repeated grade 2 and it helped her a little, "Well, sort of, yeah, it helped me in my units a bit. Just a bit."(1/4). Maths is still difficult for her, "Yeah, well I'm getting better at it but there's just some things I need to learn."(1/4). Although Maths was still an issue for her and is her least favourite subject at school, she experienced pleasure in reading, "I like reading... Yeah, I like reading about horses. Yeah, like chapter books on horses."(1/4) displaying her reading mastery, and in learning science, "I really like Science."(1/21) her favourite subject at school. Her interest in the physical world around her was evident in our third conversation when we were making pipe cleaner objects together, "A love heart. I wonder if hearts are really shaped like that. No, they're not. Why are they drawn like that then? And why do they draw stars like stars when they're actually not like that?"(3/14). Wondering about the adult misrepresentation of things in her world, what was the reason for this, what purpose did it serve.

During our second conversation Lisa's younger sister wanted to join us and use the art materials that I had brought. I told her sister, "*Well you'll have to ask [Lisa] if you can actually touch it. You can touch it. And you have to ask [Lisa] if you can use one of these. You can use one of them.*"(2/9). During this brief exchange Lisa had a smile on her face when I referred the decision-making to her and then used a very serious voice to communicate her decisions to her sister. An experience of agency.

Lisa chose to do a feeling map for jealous. This feeling was significant for her as she experienced it in her relationship with her good friend, "Well my friend and my, I mean, my friend plays with me and we have a shared area where we meet. My sister and my sister's friend and those two always um play with [good friend] and [another friend] and so...and they always jump around with [good friend] and they say [good friend]'s my favourite one and that makes me really jealous and I try and get their attention. And they think she's the best too. So I get really jealous and I try and um make them pay attention to me and stuff."(2/57). She was very conscious of her feelings about her friend and how she tried to make herself seen by the other children, "Yeah I don't really normally get jealous, I only get jealous when [good friend]'s around me."(2/58). Feelings of being lesser, which perhaps tie in with her desire that an ideal best friend be placed somewhat lesser than herself. But this feeling of jealousy happens to her in relation to a classmate as well, "A girl in my class gets lots of attention and I get jealous ...I feel jealous, cause they're better at maths."(2/59). Her classmate receiving more attention, being better at a subject she is struggling with.

Meaning

For Lisa, horses are her greatest love, "On a horse, that's my favourite place."(1/16) in the whole world. She spoke with me of the books and TV shows she enjoyed that were based on young girls and their horses, in particular 'Ghost Pony', "And there's the Pony Pals and the Ghost um Pony, yeah, there's lots of series on the Ghost Pony, ## pony it's not scary it's just about a ghost horse and the girl doesn't know that it's a ghost horse, she just thinks it's a horse. Um well it's called Star, at first she tries and she falls off and her really snobby sister came out and um... and then she went back in and um then the next time cause she went to horse riding lessons and that night she, she rode on it, and she rode on it all night. Then she told Star to stay and she ran back inside and pretended she was in bed, so she wouldn't get into trouble, it's a secret, but she told her, um, sort of friend Amy and she um, a new friend called Amy, and she doesn't believe her."(1/5). A story of connection, secrets, mastery, having a magical experience not believed by others. A story that spoke to Lisa and allowed her to vicariously live out her dream, "I wish I had a horse, I'm saving up my money for a horse."(2/26).

Lisa used to have a black Shetland pony when her family lived on a farm. She spoke of her horse, who she still misses, "I was six when I got her. And then um, when we moved out I, can't remember probably I was eight, I just turned, no probably about seven we moved out, seven and a half. *So what happened to [horse]*? Oh she sadly got sold."(1/6). She also told me stories of horses her brother and mother had had. An interest in, and love of, horses having shared family meaning. For Lisa this love of horses has remained even though her family now lives in a major city, "For my birthday

I wanted a horse, even for Christmas I wanted a horse... Well I like to go to horse riding lessons and my mum said 'we'll see' so we might find out where they are but I don't know."(1/7). To meet her own needs for connection with horses, Lisa reads books and watches TV shows about horses, and, "...sometimes I play with my sister, horses yeah."(1/7). Doing all of these things helps, "...that helps because, well it doesn't help, um getting horse, but it makes me um like horses and want a horse more."(1/8). Thus these activities feed her knowledge and desire with a shadow side of frustration as they don't bring her desire to fruition.

She also finds joy in games of fantasy at the local pool, "Well when its summer I like going to the pool cause that means I get to play mermaids and dolphins."(1/31) and she plays mermaids at the beach. She loves going to the beach, "Especially the beach. There's this beach um where the waves are are like, this is how big the waves are [waves about knee height], they're not those sort of waves [big waves] they're just ...They're just say flat and go in and out slowly like that. And sometimes the edges curl up a bit. As they go in and out. Yep it's called Clovelly Beach and it's in Sydney and there's a rock wall. There's a rock wall right at the end so you don't go washed away, right at the back. And it's like a beach swimming pool...and I go snorkelling sometimes. I saw a big black fish last summer, this long [1/2m.]. And it was it was right not too near the rock wall about um, just a bit close and and it looked really amazing cause the water was deep, not too deep and it was like you were up there and the pool's down here on the ocean."(1/33-34). Gentle waves with edges that curl, a swimming pool with a safe rock wall, and seeing a fish through the water that seemed far away. Moments of joy and wonder.

When Lisa daydreams, "I daydream that, when I'm at school, I daydream that the um school went on fire so, they had to build a new school and a better one, with swimming pools, me and my friends wish they had swimming pools."(3/3) reflecting her love of the water and her wish for access to swimming. To this she added, "Yeah with pony rides and stuff like that."(3/6) her wish for connection with horses, and being in her favourite place, on a horse.

In the winter Lisa finds joy in, "Going to the snow, I like going to the snow in winter. I play, I go tobogganing last year...It's not tall at all the mountain and its not steep. It's goes slow a bit, it goes slow. Cause that's why I like it cause it goes slow."(1/35). Having fun but knowing she's safe, like her rock wall at the beach.

Lisa likes the dark because, "...I can see nocturnal animals in the dark."(2/29) thus the dark can be a friend, not the foe that it is for Cheezel and Cerberus, as it brings gifts of animals. But the dark does become threatening to Lisa at times, "If something scary happens and then I go upstairs and its dark, I get scared, yeah."(2/53).

Lisa had many things in her life that made her happy and gave meaning, when we had finished her feeling map for happy, on which I had scribed 13 items she exclaimed, "Wow I'm, I'm a really cheer, cheerful person!"(2/37). Animals and people being kind made the world a good place for Lisa, which resonated with her happy map. Her love of animals had become her life's purpose, "I'll be a vet when I'm older, I'd like to be a vet."(2/49) a desire she shares with Cerberus and Bobby. But Cerberus and Lisa differ on one important point, sharks, so that Lisa wishes to be a vet for, "All animals, except for sharks. Some animals in the sea I don't like, like bluebottles. Jelly, sting rays are scary, and jelly fish."(2/49) and she would perhaps not gain the same joy

from visiting aquariums that Cerberus does. When she grew up she wanted her world to be a place where, "Well, less animals get sick."(3/15) and where "Um, everybody owns horses? If they want to. You can get horses in the pet shop?"(3/15).

Lisa had kept the artwork that we made during our conversations, telling me while we were looking at my photos at our final meeting, "That's [the pipe cleaner flower circle, shooting star and bracelet] still in my room...I've still got them [the playdoh figures of fruit that I had made]." (4/3) and she had previously told me that she had the pipe cleaner figure of 'Star' in her room. Momentos of special times. While looking at the photo of the 'Star' figure she very much wanted to tell me, "Horse, a horse, my horse with, very proud horse, cause its head's are in the air." (4/6). This horse figure has a blue body with an orange belly, green nose and pink tail streaming out horizontally behind her. Her head is thrown upwards and her back is arched with her front legs sweeping underneath her, as if she is about leap heavenwards.

Lisa had taken all the photos in her camera and I had developed them and sent them to her, but she had mislaid them when I visited, however she was able to tell me about some of the photos she had taken, "Oh well. I'll tell you what I took a photo of. Um the budgie, I took a photo, I'll tell you what I took a photo off. The little baby bunnies..." (4/4) "Um... Mum, Dad, [big brother] and [little sister] together on that lounge." (4/5) and her sister and herself in their Karate uniforms, and her brother in his Karate uniform. Photos of her home world; her family, her animals, her artwork.

Connection

Lisa established and sustained connections with me through her stories, through the sharing of her self; her desires, hopes and difficulties, and through her drawings and artwork.

Lisa's mother joined Lisa and me for much of our first conversation and parts of our second conversation. In our second conversation, when Lisa had finished her drawing of 'Star', she insisted, "Have to show mum. Mum, do you like this it's Star. *Oh [Lisa], it's beautiful! There's something missing though. The mane. That is a beautiful picture, you're getting better and better at drawing. Yeah.*"(2/38). This brief dialogue gave Lisa praise, direction and encouragement, which her mother employed during all their exchanges over her artwork. Interactions in which Lisa's self and developing mastery were affirmed and she was valued.

Early on in our conversations I made a blunder when asking her about her beloved horse. She was telling me, "I've seen lots of horses when you drive past, I've seen lots of horses with the black tail and *Like Jessica, [horse]? [horse]. Sorry...* Sometimes I think of her as Jessica. But she's not, she's [horse]." (1/12). She forgave me my trespass, generously offering me a way of reducing my embarrassment. We also had a hilarious interlude where we both became thoroughly confused, also of my making, "Well, I made my mum, if its hot I made my mum to go [to the local pool] but she says no but this winter I go sometimes. *You, sorry, this winter?* I've grown out of that sometimes. Oh you've grown out of that sometimes? Sometimes, that doesn't make sense. No, sort of, it does. It does? *Sometimes you still like it, sometimes you don't. Makes sense.* I don't, I'm confused now. *Are you? Yeah. Do you want to unconfuse*

yourself? How do I do that? *Are you confused about the sometimes?* Now I'm extra confused."(1/33) a very Monty Pythonesque episode, so we stopped and laughed and tried again!

For Lisa, qualities of sharing, "...sharing, sometimes, if they want to."(2/6) being nice and giving compliments are important in others. Qualities which she saw in her mother, but that she found difficult to see in her siblings, "...but about my sister and my brother being nice is a tricky question, Oh they're, they're just annoying and my brother's not nice. Um he... he teases me in a mean manner, annoying manner, a noisy manner when we're playing. And some, and he used to sneak into my bedroom and read my books."(2/7) transgressions in her play, transgressions of her privacy. She admitted that her big brother's behaviour causes her anger, "When [big brother] teases me...[big brother] annoying me."(2/41-42). "Sometimes [little sister] is annoying. Well she's immature. Sometimes when she's being silly."(2/8) which Lisa finds annoying. "But we play with each other. We, I, mean that sometimes all three of us play with each other. But [big brother] doesn't really want to play."(2/8) rather her big brother is seen as someone who gets cranky and yells and "Sometimes I um argue back."(2/10) asserting her agency. "We're not really friends, we um we sometimes hate each other. Sometimes we be silly together...I like being silly."(2/11). In our final conversation when Lisa was naming her drawings and we were looking at her angry feeling map, she called out to her brother who was in the next room, "Did you hear that [brother], angry, you teasing me."(4/10) letting him know that he had been 'named'.

Being silly is easier to do with her little sister, "... but it happens a lot with [little sister]." (2/11) a silliness that needs to connect with Lisa's idea of 'silly' (having fun) as

she had just mentioned that she became annoyed when her sister was being silly (immature). But Lisa really didn't know whether she and her sister liked the same kinds of things, "I don't know, should I ask her? Should I go and get her? What do you think she likes? I think she, well her favourite animal might be a bunny, mine's a horse."(2/11) and couldn't tell me what sort of games they played together, even though in our previous conversation she had mentioned that she and her sister 'played horses' and later in this conversation named playing with her sister as one of the things that made her happy.

Although Lisa experiences difficulty with her relationships with her peers at school, "I don't seem to have many friends..."(1/22). Like Elvis her favourite part of school is, "The part about recess and lunch is playing, that's my favourite part, play time."(1/17). Her good friend at school is another girl that she was in class with in grade 2, "...I see her on the playground a lot."(1/17), where "We play silly stuff and sometimes we make up um games."(1/19) even though, "...We don't play sort of animal games..."(1/17) like those she may play with her sister. She was unsure as to whether her friend liked animals, "I never asked her."(1/18) but assured me, "Well, we're really, really good friends because um, my sister um and my friend's sister are friends and they're also in the same class."(1/18) a shared bond, which supports visiting each other outside of school. But her good friend also has faults, "She seems like um, well she seems like she's copying me but then again maybe not, so I'm not, but she's a good friend."(1/19) copying that she finds annoying, but "Yeah but it's, I don't, she doesn't do it often so I don't really care... Yeah I don't, I don't care, forget about it, like."(1/20). Friendship founded on shared play that should not transgress the unwritten

rules of friendship, which for Lisa include copying, which can be forgiven if it is infrequent. She and her good friend have another friend, "...she's just somebody that we see on the playground then if sometimes we play with her, she's that sort of friend."(1/22). Different levels of friendship are experienced and acknowledged, 'good' friends and friends that are played with at school.

Lisa's desires in a 'perfect best friend' were, "Um would have blond hair like me and, but a bit darker, and um would be tall as me, would be the same age as me, except I would be ten and a half and she would be ten and we would um... and um, and we would be such good friends we would be almost like cousins and um we live next door to each other and, and, and we could go to each others house almost every day, and that person's name would be Lisa, and um we, we almost look like each other, and um... the person's hair, the girl's hair was up to here [shoulder length], and its, its, um like animals like me, and out of the cat family it likes tigers like me and, too many and... Would like the same sort of food and same sort of drinks which is cold water, soft drinks. And um it would hate milk like me. And it owned horses and it gave me a horse for my eleventh birthday and we lived next door to each other until we were ninety nine."(1/37). A girl who was almost a cousin, with the same interests, likes and dislikes, who would be significantly in her life until they were very old and who would gift to Lisa her dream of a horse. But a cousin who was in some ways lesser, a little younger, with hair a little less blond. Perhaps a cousin she could be better than.

Lisa experiences a lack of connection and meaning with her classmates, who she doesn't like, "The people in my class. *Yeah? All of them?* [she nods] *Yeah! How come?* They're mean to me."(1/22). They don't call her names, "...they just they're just mean,

rude. There's this real mean girl, she thinks I ignore her but I don't and cause she just does complaints and she's snobby, she, yesterday she um she growled at me, well she yelled at me, yeah... I hate her. Like everyone in my class likes each other but except I hate everybody. Like everybody in my class likes each other except for me and I don't like them, so, yeah."(1/23). A feeling of being excluded and disliked, which she returns, perhaps as a strategy to resist their positioning of her. She likes her teacher, "...he smiles all the time, even when he talks."(1/24) and feels that her teacher tries to maintain good behaviour, "He, he just well... he, he's, he just claps and, if somebody tells on somebody and tells him he just stops the class by clapping and tells them, be nice or...there's this rule in our class not to um ah, I forgot what its called, but its um something like, don't ins, in...Insult people, mind your own business or something like that...but it doesn't work, it works, it, I listen to him but um the class just still be's rude to me."(1/24). Adult authority not impacting on her classmates' behaviour.

Surprisingly for me, her antagonistic relationship with her classmates does not spill over into her overall feelings about school, "it's just the class, I hate the class."(1/24) as she still likes going, "I like school" (1/26) reflecting the meaning she finds in certain subjects and her enjoyment of recess times, "For the playing time in it... and get away from the bullies."(1/25). Talking about these issues made Lisa teary-eyed and it was obvious that these classroom moments were difficult times for her to endure, times of being made other when she wanted to be accepted, of feeling very alone and unwanted, but she considered these times annoying rather than hurtful, "Well um I don't, I don't care about them until I go to school and they say something to me, so I don't pay attention to them sometimes. They don't, they don't be annoying me, to me

often...it doesn't hurt but, it just gets annoying, it just gets annoying."(1/26) though her frustration and the sadness in her eyes belied what she was saying about not feeling hurt. It seemed that she was able to contain the emotional impact of these experiences, as she told me that she didn't think of them outside of school. People being mean make the world a bad place for Lisa, resonating strongly with her school experiences.

But Lisa doesn't seem to get angry, "Some people when they're angry they go red in the face but I don't do that. *What happens to you?* I don't know I haven't been angry in a long time."(2/40). However, on pondering further she said, "It's a hard thing, I don't know what makes me angry, um... when people laugh at me, like they laugh at me cause I don't think I did something, I don't know. You know how being mean laughing not being nice laughing? (2/42), being laughed at/ridiculed by others, an injustice of behaviour. Adults that "act mean"(2/43) have featured in her life at school, "[Teachers that]Yell a lot. There was this teacher at our school called [teacher] she was so red in the face she yelled a lot she was really mean. The whole school didn't like her. Our librarian at our school is really mean. I'm too frightened to talk to her sometimes. She yells, she insults people."(2/43). Teachers yelling and being insulting to the children in their care and the injustice of such behaviour. Transgressions of responsibility and respect by adults in positions of authority. As Lisa told me later, "Feeling unsafe in a safe place."

I talked with Lisa about my negative experiences of school and what I had done to avoid going. She was very interested in this, asking me questions about what I did, whether my mother had believed that I was 'sick' so often and, "Why did you hate it, did you ever sometimes go to school?"(1/27), wanting to know whether the day of the

week or the time of the term had made it easier to go, "So did you go to school on Fridays? ...On the last day of school did you go? cause sometimes on the last day of school you don't really do work"(1/27) and whether I liked any of the work and if so did that make me feel like I'd missed out, "Then what would you do if um your sister came home and said 'I did English at school', would you get a bit upset cause you missed out on English?"(1/28). Very insightful questions which showed an empathic understanding of my experience (Bettelheim, 1974) and making suggestions for moments at school that might have been easier for me to bear and also suggesting that there were times at school that were worth experiencing despite how difficult it may be.

Birthdays and Christmas are special times for Lisa, times which make her happy, times of joy and connection and giving. Hugs and laughing are also things that make Lisa happy, also speaking of connection and of joy. Lisa told me a story of joy, using the colours in the pencil box as characters, "OK. Once yellow green didn't have a friend so it was really sad then, yellow came along and said why are you sad, do you want to play and it said yes. That's a really happy story."(3/19). Happiness through friendship, a theme that resonates in many of Lisa's stories of her life and her wishes.

Happy's shadow side of sadness is felt by Lisa when she hurts herself or gets into trouble, times of disconnection from the important adults in her life (emotional pain), and times of physical pain. She also felt sad when she said goodbye to her horse, when, "...somebody bought the kittens."(2/48) when she was six years old, and when one of her animals dies, "I bury my animals in the backyard when they die and I bury a flower on it, on top of them. We have a sort of funeral for it."(2/50) which she would be doing again as her white rabbit had recently died. Times of loss of her loved animals.

Faith

Lisa and her family are Catholic, "A, I don't really know religion, what that means but um...I'm Christian."(1/39). She doesn't learn about religion or other faiths at school, "We don't, we don't learn that, this, I go to a public school..."(1/39) nor about the divinities in her own faith, "No I go to Mass and learn it [about God and Jesus]. Yeah I like Mass sometimes, when I understand it."(1/39). When I asked her what she knew about Jesus, she replied, "He's kind. He had a mother called Mary and a father called Joseph, did he?"(1/38) and God, "God was his father, sort of had two fathers."(1/39). The kindness of Jesus and his family relationships being the most meaningful things about him. With a suggestion that Mass was only sometimes meaningful, when understandable. Not a lived faith, rather a weekly part of family life, a ritual she participated in but one that did not provide support or comfort or joy or wonder in her daily life, as it did for Cerberus.

Lisa believes in, "I believe in angels and tooth fairies and I like believing in mermaids."(2/42) which seemed to say that angels and tooth fairies were very real, but mermaids were fantasy.

Courage

Lisa chose to do a feeling map for 'scared'. Her discussion included, "And ghost stories." "...The Ghost Horse and the Haunted Travellers, they come in different names the two series, so just write. Write scary books. So they make me scared. Cause its about ghosts, well not about ghosts just...sometimes its not scary. *Cause you like the ghost, you like the Star books and they're not scary, are they?* No but the person that was following them and stuff was a man, she was scared and then but she found out it was

the owner, they died in a fire together, and the boy's name was Michael."(2/54) so that even though the ghost horse was loved by Lisa, the man following Star and the girl was a scary character until Lisa knew who he was. Lisa identified with the girl's fear. Another thing that scared her was, "Nightmares, I haven't had them in a while."(2/54).

Lisa's primary fear was being alone and the only thing that helped her, "Being not alone and that's the only thing...Its hard to describe, that's all that helps."(1/55). Courage being found in the presence of another. Does this point to Lisa not feeling agency? Not feeling a strong sense of self?

When Lisa and I talked about courage she told me, "I don't know what I'm brave about. Some people are scared of the dark. I'm not scared of the dark. I used to be, but now I'm not scared anymore."(3/19). Now, "I like the dark sometimes."(3/22) harkening back to her liking of the dark because the nocturnal animals can be seen. Not crying when feeling like crying is being brave, as Lisa told me, "That's a bit brave. I, its hard to hold tears [back]." (3/22-23) as she talked about the girl in 'Ghost Pony' who held back her tears when 'Star', "disappeared forever"(3/22). Her next story of bravery also related to animals, "Um... once I got bit by a swan... it was an accident, yeah. So I was going to feed it, um some bread, and, um instead of throwing it came up and took it off. Well it didn't really hurt that much cause I pulled away, so it actually touched me."(3/25). A story of the unexpected, of facing potential danger, which scared her only, "A little."(3/25). Courage experienced in the everyday.

Lisa's experiences with her classmates featured in her courage feeling map, "[Lisa] at school, um is, gets teased by kids but, um, is brave."(3/26) which caused her to ask me again about my school experiences, "Did you go to school when you got

teased?"(3/26) asking me further about what happened when I stayed at home, whether my mother was angry, and when I had stopped doing it. These questions wove into a discussion on feeling other at school, "Na, I have friends. I have one."(3/28) reminding me of Chontelle's comment about neighbourhood friends, and of watching others who seem to make friends easily, "*And you know when you watch other kids and they, it seems to be really easy for them to make friends and to get people to laugh and. It seems by the very minute they just make friends. Yeah, just happens. They just walk up to the person and start playing. And you just wish you could be like that too. Yeah, I do. Yeah, me too.* Some person in my class has six friends. Yeah, most of those six friends are in her class. Only two girls in her class are not her friends. And a couple of girls not in her class are her friends. She has a lot."(3/29) and we sat there wondering what the secret was to other children being able to make friends so easily.

Hopes and Dreams

In our second conversation Lisa had talked about wanting to be a vet, and she brought this up again when talking about daydreams in our third conversation. "Yeah, I'd like to be a vet when I'm grown up (3/4)... I think about um me helping animals..."(3/5) and her love of and identification with animals spills over into her daydreams in other ways, "...sometimes I daydream about me being an animal and sometimes I wish I was an animal. I mainly dream that I was, I'm a horse cause that's my favourite animal. Yeah running really fast. Sometimes I wish I was a tiger, or a lion. *And why would you like to be one of them?* Um... they live in the wild. Really do anything they want."(3/5). Animals who are free, who have no human rules to live by, who live in unfettered realms, who can run fast and are powerful, being in their body.

Her hope for a horse wove through all our conversations, not surprisingly ending up on her hope feeling map, "Hope I'll get a horse." (3/30) and became part of the story that she told for hope, once again using the colours in the pencil box for her story characters, "Raw sienna. Raw sienna was sad cause she was hoping for, a horse, a beautiful brown horse but that was in her dreams, and one night she went to sleep and dreamt of a beautiful horse. It was her birthday coming up and her friend was going to get her a birthday present and... she, she didn't know that she was getting her a beautiful brown horse named... Golden Brown. So, dark violet bought a golden brown horse, called Golden Brown horse cause it was ## golden brown horse so raw si, Sienna, raw sienna was, was and was, hoping for a horse and one day, and there was a dawn but and there was um somebody at the door she went to see who it is and... she she said, oh come in, and behind, and behind her back there was, behind dark violet's back her friend, there was a horse and she went 'yeah!' and she started riding on it and they shared the, and they shared the horse." (3/32-33). A story of friendship and being given her dream, as in the 'best friend' story, themes that occurred in Lisa's stories over and over again.

Lisa also daydreams about, "Um I daydream about... um... sometimes I daydream about um one day finding a mermaid at the beach." (3/6). With me acting the part of the audience/enquirer she constructed a story for me about meeting a mermaid while walking along the beach, "And I'm the only one there with my family. And I'm with my family, and we're the only ones there cause we came really early in the morning to go to the beach, and um, I spotted this um big tail in the water, you know how mermaids got a fish tail. So, um, I and its really um big, and I and I wonder what its

doing in the shallow end of the water so um, then I go into the water and I, and then I see the mermaid. As there's a tail and then I see. Um, a, then straight away I see a, a humans head pop up, and then they crawl onto the beach sand and I see the tails attached to the body, and it's a mermaid. The mermaids scared at first, then I say hello to it, and then it turns, sometimes I think mermaids have powers, so it turns me into a mermaid and we both went swimming with the dolphins. And I collect shells. Um I, I collect them when I'm swimming. [The shells are] Really big. Well I came across a gold one. And the mermaid, and the mermaid found a silver one, and the mermaid kept it. The mermaid left it there cause its always in the ocean. She left it cause its always in the ocean she can easy swim there. And I asked them what, what they do for, what it does for school and then it, showed me where the school shows the mermaids how to swim. She learns maths, she learns um, the names of shells."(3/6-8). The mermaid lives in a cave with her family, and she likes to, "Um go onto the beach, play with dolphins. Follow whales." (3/9). A beautiful fantasy story of a mermaid befriended, who shows Lisa her world, which is not unlike her own, with school where she learns maths and science, and a family and a home. But a mermaid who can swim and play with dolphins and follow whales, animals of the sea. A story which although it is a daydream comes to life for Lisa as she 'likes to believe' in mermaids and their special powers, their alterity and agency. Experiencing another home, a parallel existence within the water she loves. The ocean feeding her soul with knowledge and fantasy (Moore, 1996).

Lisa's ability to engage in (and her obvious pleasure in) imaginative storytelling and in imaginative play while she herself was at the beach or in the local swimming pool speaks of a richness in her being that she is able to access, and finds joy in accessing.

Her creativity enabling her to give herself pleasure, whether or not someone else is present. Perhaps for her it reduces her feeling of loneliness and otherness, and stimulates her imagination to create more complex and satisfying moments (Singer, 1973). These moments give ways of acting out desires, of feeling empowered through knowing what will be created and having the control to alter the fate of that which is created, of being part of something greater than the self. As with Cerberus and his creative projects, these enacted stories appear to hold a meaning far greater than simple pleasure.

Trust

Trust to Lisa means, "That means... they're a good person. Like um if they help people."(3/38) echoes of Elvis, which she explained by saying, "[little sister] helps people if you ask her."(3/38). Lisa does, "I trust my mum and dad."(3/36) but this instinctive trust was not extended to her sister, "Um I sort of trust [little sister]. [little sister]'s cheeky sometimes."(3/37) a qualified trust, "[little sister]'s sometimes easy to trust."(3/41) but Lisa needs to take care with what secrets she shares with her. And her brother was not trusted, "Na he's really mean sometimes."(3/37) this meanness causing her to be wary of him. Lisa didn't trust anyone at school but was able to trust her good friend, "She's trustable. I trusted her before."(3/38). But her trust of her good friend is not absolute, "Um yeah she can keep a secret. But she tells her sister sometimes. I never tell a secret, its just bad. Um if we have a argument we don't want, we never tell our parents. So um, and one day [good friend] told her sister."(3/40) a transgression of their friendship as little sisters may abuse this trust, "You know how cheeky [little sister] gets."(3/40). The importance of keeping secrets reflecting Deatherford's feelings of privacy and needing to consider whether friends could be trusted to keep that privacy.

I asked Lisa whether I could trust her and why, "Yes. Because everybody trusted me once um, I'm the only one that remembers um things like from when I was two so they um my mum and dad trust me to remember."(3/39) having been already trusted by adults. Being trusted with the family remembering/memories, the keeper of family history.