5.3 DATA COLLECTION PROCEDURES

The procedures followed for Pilot Study Three were based on those developed and refined in the previous pilot studies.

5.3.1 Flow chart

A daily 'flow chart' of both pilot study and NDT Course events was constructed for the period from the beginning of May to the end of August 2009. This document ordered the progression of events from the initial mail out of fliers to families in May, through to the final follow-up filming.

The following aspects of the study procedures were included in a flow chart. Specific examples of these events included:

- Distribution of the various consent forms for parents and therapists, towards collecting and using videotaped and written data
- Specified data collection points
- Detailed preparation for film periods
- Course requirements, such as the organization required for the NDT treatment practicums.

5.3.2 Development of Goal Attainment Scaling (GAS) score sheets

The development of the GAS score sheets occurred in the following two-stage process.

First, as part of the initial NDT Course training, each participant therapist was assigned to two of the twelve children for whom they would provide NDT

intervention. After instruction in goal setting from the instructors, discussion with parents and the children about desired functional outcomes to intervention, and observation of performance using task analysis procedures, the therapists were asked to generate one or two functional, measurable intervention goals. The goals that were generated were 'checked' by the parents for relevance, and by the instructors for clarity and feasibility. These goals reflected the expected outcomes for children over the five weeks of treatment practicum of the course, and included all conditions and contextually important details, such as use of the child's own equipment. Table 5.5 lists examples of expected outcomes relative to each of the children, and illustrates how the GAS *target areas* were initially expanded to reflect *intervention outcomes*.

Table 5.5: Intervention goals developed by therapist participants as part of the GAS development process

Child	Goal area	Functional goal
1.	Movement forwards for assisted transfers from wheelchair	J53, J51 or J52 will slide hoop forward along table over upright wheelchair, sustaining bilateral palmar grasp with elbow extension, allowing forearm support, whilst sitting in wheelchair maintaining visual fixation on toy for 15 seconds to move toy 5cms (2 inches) distance - 2 of 3 trials by 7/17/09 [This 'functional' goal incorporates a game to encourage movement forward in her wheelchair; this represents 'forward movement' as a component in assisted daily care tasks such as required in dressing, and transitions out of her wheelchair]
2.	Eating with a fork	- while sitting on bench seat at the low table (allowing for elbow support), & resting right arm on table - will reach for the fork with left hand, completing radial palmar grasp and bring to mouth, sustaining neutral head, trunk, pelvic alignment, and hip/knee flexion 90 degrees, 2 out of 3 times by 7/17/09
3.	Finger feeding	- will reach out for the food/biscuit with her left (or right) hand, looking towards the biscuit, with her shoulder girdle forward of her hips, spine extended - and take the food to her mouth within 15 seconds, in 2 of 3 trials by 7/17/09.
4.	Reaching to grasp toys 'beyond her reach', at the side. GOAL A	- will reach to & grasp a desired toy by crossing the midline with either left or right hand to grasp the toy held 'arms length' away from her contralateral shoulder*, ipsilateral hand restrained, seated on blue bench, within 5 seconds, in 2 of 3 trials by 7/17/0
4.	Reaching to grasp toys 'beyond her reach' across midline. GOAL B	- will reach to & grasp a desired toys by reaching out sideways with either left or right hand to grasp toy held 'her' arm's length away + 10cm (3.9 inches) lateral to tips of her fingers * seated on blue bench, with assistant's support at pelvis, within 5 seconds, in 2 of 3 trials by 7/17/09
5.	Communicating using a Dynavox	- will use '2 word phrases' on her Dynavox communication device (positioned on height adjustable table left of midline, 2 feet away from chest) reaching with weight shift forward to press keys on the Dynavox with her left index finger, while sitting on 'brown bench' with feet flat on the ground; then reaching forward with left or right hand to flick down the cards of the game. 3 of 5 trials by 7/17/09.
6.	Standing to use a bat.	- from stance position, subject will . . . hit a balloon with a bat; standing with heels down, neutral leg and trunk alignment; within 5 seconds, in 3 of 5 trials, by 7/17/09.
7.	Executing 'Ronde de Jambe' ballet move (for ballet class).	- will complete a ballet move – 'Ronde de Jambe" - (involving flexing her right hip with full knee extension and right ankle plantar flexed until her right big toe touches the ground, and then circumduct her right hip to trace the largest semi-circle possible until she reaches right hip extension in abduction/adduction neutral) while sustaining her left hip over her left ankle with her knee extended and sustaining head, neck, trunk and pelvic upright alignment, while holding the backrest of the chair with her left hand for light support, with the back leg of the chair positioned 20 cm (7.9 inches) from the lateral aspect of her left foot. She will complete 2/3 trials successfully

		by the 17/9/09
8.	Undoing screw top lids	will stand upright* with feet apart, holding his own water bottle** with his left hand*** and using his right hand to unscrew the lid, in 3/5 trials by 7/17/09.
9.	Walking to throw a ball through a hoop. GOAL A	- will walk from a starting line between 2 lines of coloured tape placed 50 cm (19.7 inches) apart, for 2 metres (6.5 feet), with body alignment, and stop at the red line, to throw a ball through the yellow hoop, in 3 out of 5 trials by 7/17/09
9.	Vocalising with clarity GOAL B	- will maintain standing for the duration of 'Happy Birthday' song and blow out 3 candles with 'lip rounding' in 3 out of 5 trials by 7/17/09
10.	Climbing a step to reach a toy	- will climb up a 10 cm (3.9 inches) high step, leading with his right leg independently and reach out for a toy, left hand held for moderate assistance while climbing up, within 5-10 seconds, while maintaining neutral upright body alignment, (AFO's on) in 2 of 3 trials by 7/17/09
11.	Donning socks	- will independently put on her right mid-calf length sock, handed to her right hand, 'pre-crumpled' by therapist, on her right foot while sitting on the green chair, without arm supports, with her left foot supported on the floor with her right leg in 'tailor position', using her left hand to stabilise her sock while right hand pulls it up in 3 minutes, in 2 of 3 trials by 7/17/09
12.	Standing at a table to use hands	- will reach with his right hand to pick up and eat 2 of 3 jellybeans, one at a time, from snack container on the table, standing with upright trunk alignment (trunk not touching the table), while his left hand (only) stabilises on the table, by 7/17/09

The therapists were asked to fill out detailed information that would assist the development of a filming plan for each child to be used to record their performance of the task at pre- to post- and follow-up tests (Appendix XXIX). This information included details related to the equipment required, the position of equipment and child, and assistance required.

In the second stage of GAS development, the researcher further expanded the goal statements outlined in Table 5.5 for scoring by independent raters. GAS scoring charts were constructed with statements that incorporated descriptions of the child's best performance at pre-, post- and follow-up filming. Scale construction followed the guidelines of GAS together with the researcher's estimation of the child's performance level described in earlier chapters. For example, pre-test

behaviour was reflected in the -2 level of the scale, goal task behaviour entered at 0, and goal related behaviour that was considered 'much more than expected', was reflected at the highest level, + 2 (Kiresuk, Smith, & Cardillo, 1994). Also, as recommended by these authors, GAS subscales were created for measurement of a variety of goal related parameters per child, per trial. Examples of subscales included a specific aspect of goal related postural control or hand function (Kiresuk, Smith, & Cardillo, 1994).

Tables 5.6 to 5.9 are four examples of Goal Attainment Scaling charts, including either two or three subscales, that were developed through this two-stage process. See Appendix XXXi-ii for examples of GAS charts with four subscales.

Table 5.6: GAS chart with subscales for Child 2 (J93,J91 or J92). Parameters for Gas Scale measurements for this goal are 1.) Fork to mouth, 2.) Body alignment.

GAS CHARTS: **J93, J91 or J92 - please ensure this code matches the DVD you are scoring!**

Activity limitation: *Eating with a fork*

Functional measurable goal / outcome:

J93, J91 or J92 - while sitting on bench seat at the low table (allowing for elbow support), & resting right arm on table - will reach for the fork with left hand, completing radial palmar grasp and bring to mouth, sustaining neutral head, trunk, pelvic alignment, and hip/knee flexion 90 degrees, 2 out of 3 times by 7/17/09

Other goal conditions: Bench seat 19 cm (7.5 inches) high; low table 38cm (15 inches) high; fork on table in midline – piece of donut on fork; AFO's and shoes on; 'standby' supervision only.

Parameters for Gas Scale measurements for this goal 1. Fork to mouth, 2. Body alignment

ATTAINMENT LEVEL: Please ✓1 level (group of statements) ONLY in each blue column to right of each of the 2 following Gas Subscales for this goal - from what you have observed in the DVD. *Then please email me your results.*

GAS SUBSCALE 1 – Fork to mouth	Levels	GAS SUBSCALE 2 – Body alignment	Levels
With minimal or no assist in initially placing the fork for grasp, the subject is able to grasp the fork (with radial palmar grasp) and with elbow supported on the table, take it to his mouth – and place the fork with food inside his mouth to remove and eat food, on 2 occasions within the trial.	+2	'Alignment' during task includes neutral alignment of: - Head/neck (as required) - Shoulder girdle - Thoracic and lumbar spine (as required) - Pelvis neutral to anterior tilt - Right lateral weight shift - Feet flat on surface - Some rotation forwards on left side towards fork	+2
With minimal or no assist in initially placing the fork for grasp, the subject is able to grasp the fork (with radial palmar grasp) and with elbow supported on the table, take it to his mouth and place the fork with food inside his mouth, to remove and eat food on 1 occasion within the trial.	+1	'Alignment' during task includes neutral alignment of: - Head/neck (as required) - Shoulder girdle - Thoracic and lumbar spine (as required) - Pelvis neutral to anterior tilt - Right lateral weight shift - Feet flat on surface	+1
With minimal or no assist in initially placing the fork for grasp, the subject is able to grasp the fork (with radial palmar grasp) and with elbow supported on the table, take it up near to his mouth - or with forearm/wrist support as well, move his mouth down to the fork.	0	'Alignment' during task includes neutral alignment of: - Head/neck (as required) - Shoulder girdle - Thoracic and lumbar spine (as required) - Pelvis - Right lateral weight shift - Feet on surface	0
With minimal or no assist in initially placing the fork for grasp, the subject is able to grasp the fork (with radial palmar grasp) and with wrist/forearm support on the table, move the fork a little towards mouth, but predominantly move his mouth towards the fork.	-1	'Alignment' during task includes: - Intermittent head/neck flexion - Shoulder elevation - predominantly - Thoracic and lumbar flexion - predominantly - 'Upright pelvis' - Right lateral weight shift - Feet remain (at least predominantly) on the surface	-1
With minimal or no assist in initially placing the fork for grasp, the subject is able to briefly grasp the fork (with radial palmar grasp).	-2	- 'Alignment' during task includes: - Head/neck flexion - predominantly - Shoulder elevation - predominantly - Thoracic and lumbar flexion - Posterior tilt of pelvis - When subject begins to fall to the right side, he attempts to recover by flexing upper body/shoulder girdle and upper extremities forwards; his feet leave the ground.	-2

Table 5.7: GAS Charts with subscales for Child 5 (**J103, J101 or J102**).

GAS CHARTS: J103, J101 or J102 please ensure this code matches the DVD you are scoring!

Activity limitation:
Use of alternative augmentative communication device.

Functional measurable goal / outcome:
J103, J101 or J102 will use '2 word phrases' on her Dynavox communication device (positioned on height adjustable table left of midline, 2 feet away from chest) reaching with weight shift forward to press keys on the Dynavox with her left index finger, while sitting on 'brown bench' with feet flat on the ground; then reaching forward with left or right hand to flick down the cards of the game. 3 of 5 trials by 7/17/09.

Other goal conditions: Verbal offer of help with using Dynavox as required.
Verbal prompt as required for weight shift forwards and feet flat on ground &/or occasional physical prompt for the latter (taps on knees).
The phrases will describe attributes of the person she chooses for this adapted game of 'Guess Who' (e.g.' red hair'). She then flicks down the cards of people who don't possess this attribute. The game is placed right of midline, 2.5 feet from chest.
Parameters for Gas Scale measurements for this goal 1. Words per phrase. 2. Weight shift forward 3. Feet orientation

ATTAINMENT LEVEL: Please ✓1 level (group of statements) ONLY in each blue column to right of each of the 2 following Gas Subscales for this goal - from what you have observed in the DVD. *Then please email me your results*

GAS SUBSCALE 1 – Words per phrase	Levels	GAS SUBSCALE 2 – Weight shift forward	Levels	GAS SCALE 3 – Feet orientation	Levels
Subject uses a 3 word phrase on her Dynavox communication device with minimal verbal assistance to type the words.	+2	Subject shifts her weight forward, assisted by all of the following: - Activity sustained in both anterior pelvic tilt & spinal extension - Weight shift laterally to left or right - Rotation forward to right or left side	+2	Subject sits on the bench with feet flat on the ground - both feet with toes pointing forwards throughout the trial.	+2
Subject uses a 3 word phrase on her Dynavox communication device with moderate verbal assistance to type the words.	+1	Subject shifts her weight forward, assisted by all of the following: - Activity initiated in both anterior pelvic tilt & spinal extension - Weight shift laterally to left or right - Rotation forward to right or left side	+1	Subject sits on the bench with feet flat on the ground - at least one foot with toes pointing forwards throughout the trial.	+1
Subject uses a 2 word phrase on her Dynavox communication device without any verbal assistance to type the words.	0	Subject shifts her weight forward, assisted by - Some weight shift laterally to left or right - And / or, some rotation forward to left > right side - And / or, support of her right forearm on her thigh / or right forearm & hand on the table for part of the time AND - spinal flexion.	0	Subject sits on the bench with feet flat on the ground throughout most of the trial.	0
Subject uses single word 'phrases' on her Dynavox communication device without any verbal assistance to type the words. .	-1	Subject shifts her weight forwards assisted consistently (ie throughout trial) by right hand support on table - and spinal flexion.	-1	Subject sits on the bench with feet partially flat on the ground - ie one or both foot move across the surface about half the time.	-1
Subject types 2 single words on her Dynavox communication device with verbal assistance to type the words .	-2	Subject shifts her weight forwards assisted consistently (ie throughout trial) by right hand (or hand & arm) support on table - and spinal flexion.	-2	Subject sits on the bench with both feet moving across the surface & at least one foot moving fully off the surface at least once.	-2

Table 5.8: GAS chart with subscales for Child 10 (**J123, J121 or J122).**

GAS CHARTS: J123, J121 or J122 please ensure this code matches the DVD you are scoring!

Activity limitation:
Climbing steps

Functional measurable goal / outcome:
J123, J121 or J122 will climb up a 10 cm (3.9 inches) high step, leading with his right leg independently and reach out for a toy, left hand held for moderate assistance while climbing up, within 5-10 seconds, while maintaining body alignment, in 2 of 3 trials by 7/17/09

Other goal conditions:. Verbal cue to hold hand and climb up the step with right leg and reach for a toy with right hand; wear right AFO; toy held above shoulder height at approximately 135 degrees flexion (& shoulder neutral in the frontal plane, with elbow extended)

Parameters for Gas Scale measurements for this goal: 1. Body alignment 2. Assistance given.

ATTAINMENT LEVEL: Please ✓1 level ONLY in each blue column to right of each of the 2 following Gas Scales for this goal - from what you have observed in the DVD. *Then please email me your results.*

GAS SCALE 1 – Body alignment	Levels	GAS SCALE 2 – Assistance given	Levels
Child chooses to *jump* onto the step, appears to take weight equally between left and right legs and reaches out for the toy (within 5 – 10 seconds): on the step he continues to take weight equally between left and right legs – in jumping and standing.	+2	Child chooses to *jump* onto the step and reach for the toy and to play/*jump on* the step whilst left hand is held for moderate assistance; and 'runs' off the step with no assistance.	+2
Child chooses to *jump* onto the step - rotating towards the left side - and reaches out for the toy (within 5 – 10 seconds): on the step (after jumping again) he appears to take weight equally between left and right legs.	+1	Whilst climbing up the step, and reaching for the toy *only*, subject's left hand is held for moderate assistance; child *squats* to play with no assistance and steps back down off the step with no assistance.	+1
Subject climbs up the step, leading with his right leg independently, - elongating his trunk on the left side - and reaches out for a toy (within 5 – 10 seconds): during standing/playing on the step he takes weight equally between left and right legs.	0	Whilst climbing up the step and reaching for the toy *only*, (not during standing/playing or getting down from the step), subject's left hand is held for moderate assistance.	0
Subject climbs up the step, leading with his right leg independently, elongating his trunk on the left side - and reaches out for a toy (within 5 – 10 seconds): during standing/playing on the step weight is born more by the left leg than the right leg.	-1	While climbing up the step and reaching for the toy and getting down from the step, subject's left hand is held for moderate assistance; hand not held while standing on the step & playing.	-1
Subject climbs up the step, leading with his right leg independently, with lateral trunk flexion to left - and reaches out for a toy (within 5 – 10 seconds): during standing/playing on the step weight is born predominantly by the left lower extremity.	-2	While climbing up the step. reaching for the toy and standing & playing on the step (throwing) and getting down from the step (dragging right foot), subject's left hand is held during all, for moderate assistance.	-2

Table 5.9: GAS chart with subscales for Child 11 (**K23, K21 or K22).**

GAS CHARTS: K23, K21 or K22 please ensure this code matches the DVD you are scoring!

Activity limitation:
Donning her socks

Functional measurable goal / outcome:
K23, K21 or K22 will independently put on her right mid-calf length sock, handed to her right hand, 'pre-crumpled' by therapist, on her right foot while sitting on the green chair, without arm supports, with her left foot supported on the floor with her right leg in 'tailor position', using her left hand to stabilise her sock while right hand pulls it up in 3 minutes, in 2 of 3 trials by 7/17/09.

Other goal conditions: Verbal cue "you can use your left hand to help too" after handing the sock to her. Benik thumb orthosis on.

Parameters for Gas Scale measurements for this goal 1. Left hand usage & time taken. 2. Postural control.

ATTAINMENT LEVEL: Please ✓1 level (group of statements) ONLY in each blue column to right of each of the 2 following Gas Subscales for this goal - from what you have observed in the DVD. *Then please email me your results.*

GAS SUBSCALE – left hand usage & time taken	Levels	GAS SUBSCALE 2 – postural control *while donning sock*	Levels
Subject uses her left hand to stabilize & manipulate her sock - approximately100% of the time - while her right hand pulls it on and up, within 1 – 4 seconds	+2	Subject maintains trunk rotation to the left with tailor sitting position with her right leg and dynamically weight-bears on left buttocks during sock donning process; sits forward so left foot fully supports on the floor, facing forward	+2
Subject uses her left hand to stabilise & manipulate her sock - approximately 100% of the time - while her right hand pulls it on and up, within 5 – 9 seconds	+1	Subject maintains trunk rotation to the left with tailor sitting position with her right leg and weight-bears on left buttocks > right; sits forward so left foot fully supports on the floor, facing forward.	+1
Subject uses her left hand to stabilize her sock – approximately 100% of the time - while her right hand pulls it on and up, within 10 – 15 seconds.	0	Subject maintains trunk rotation to the left with tailor sitting position with her right leg and weight-bears on left buttocks > right; sits forward so left foot fully supports on the floor.	0
Subjects uses her left hand to stabilise her sock – a 'little more than 50%' of the time - while her right hand pulls it on & up, within 15 - 25 seconds.	-1	Subject maintains trunk rotation to the left with tailor sitting position with her right leg, though weight-bears less on left buttocks than right; if she supports through her left foot on the floor, it is generally through the lateral border only (with foot medially rotated).	-1
Subject uses her left hand to stabilise her sock - less than 50% of the time - while her right hand pulls it on and up, within 15 – 25 seconds.	-2	Subject weight-bears less on left buttocks than right, and if she supports through her left foot on the floor, it is generally through the lateral border only (with foot medially rotated).	-2

5.3.3 Filming schedules

During initial phone discussions, parents were invited to choose the most suitable times for filming for ½ hour to ¾ hour appointment times (between 10am to 4.30pm) during three weekends for pre-, post- and follow-up filming. These appointments with details about filming were then sent out for confirmation, with the parents' information packages (Appendix XV1I).

The film appointments occurred at the start of course treatment practicums (pre-tests), immediately after practicums had ceased (post-tests), and then six weeks after the completion of the course (follow-up). There were some small adjustments made to the schedule, according to parents' requirements on each occasion. All children attended all the filming sessions, with the exception of three children for follow-up filming. One child was unwell, one was unable to cooperate with the demands of filming, and one child had lower extremity Botox following the post-test filming, and was excluded for this reason.

5.3.4 Coding of data

Children were assigned codes for privacy reasons and blinding for rating by experts. Similar to the procedures described in Pilot Study Two, the children were identified to blinded raters only by their codes, which were filmed at the commencement of each of their respective videotapes (Plate 5.5c).

The key to the assigned codes was as follows: the letter 'J' was assigned to the group of children whose surnames began with letter A to M. 'K' was assigned to children with surnames N to Z. Pre-test filming was assigned a code of '3', post-

test filming a code of '1', and follow-up filming, '2'. Children were numbered one to 12 in no particular order. For children who may have had two goals, 'A' and 'B' were added to the code for the first of these children, and in the case of the child throwing a ball through a hoop 'H' was added; and 'C' was added to the code for blowing out candles. The coding of all the children and the filming sequences is found in Table 5.2.

5.3.5 Sequence of filming procedures

5.3.5.1 Trial filming

Two weeks prior to the commencement of the course, a 'trial filming' with a colleague's' typically developing' child served as a practice of all the steps involved in filming the children in the study. This practice included rehearsing the duties of the researcher and filming assistant, and setup of the film equipment and floor grid. This child had chosen two 'daily tasks' of hopping across the grid (Plate 5.7a) and blowing up a balloon with a pump, to then release above him!

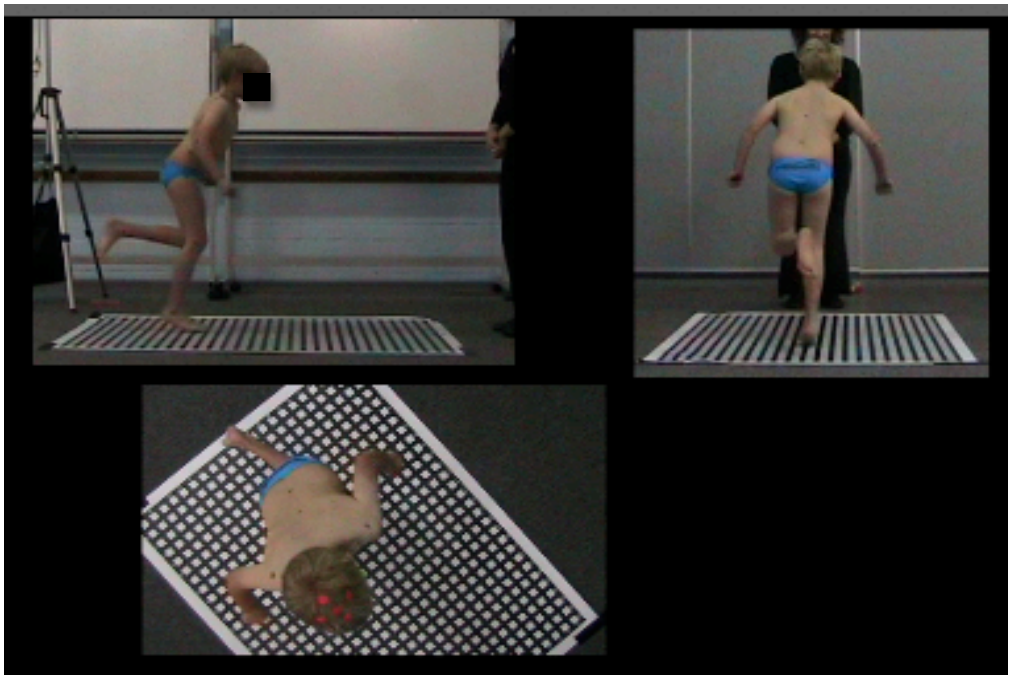
This trial included all the suggested refinements that were recommended at the conclusion of Pilot Study Two, and included the following:

- Development of 'information forms' for parents and therapists regarding filming
- The use of a pre-printed floor grid
- An 'easier' system of overhead camera mounting
- Provision of three Mini DV video tapes per child at each filming occurrence.

The 'trial filming' with a colleague's child, enabled us, as a team, to practice and refine all the steps involved in filming the children at each part of the study and resulted in further slight modifications to filming procedures (Table 5.10).

Table 5.10: Modifications to filming resulting from trial

Steps in filming		Changes required
Video footage and notes from the trial were analysed. Most aspects of the steps in filming went according to plan, with the exception of the following three steps:		
1.	Overhead camera window alignment.	Window was subsequently rotated slightly and temporarily fixed in place for each of three film periods to enable complete filming of grid below.
2.	Floor grid moved slightly when 'hopped' across.	Edges of grid were taped to floor with cloth tape.
3.	Time to accurately set up film equipment.	All floor measurements in the room including distances from corners and doors were mapped out and recorded for faster replication.



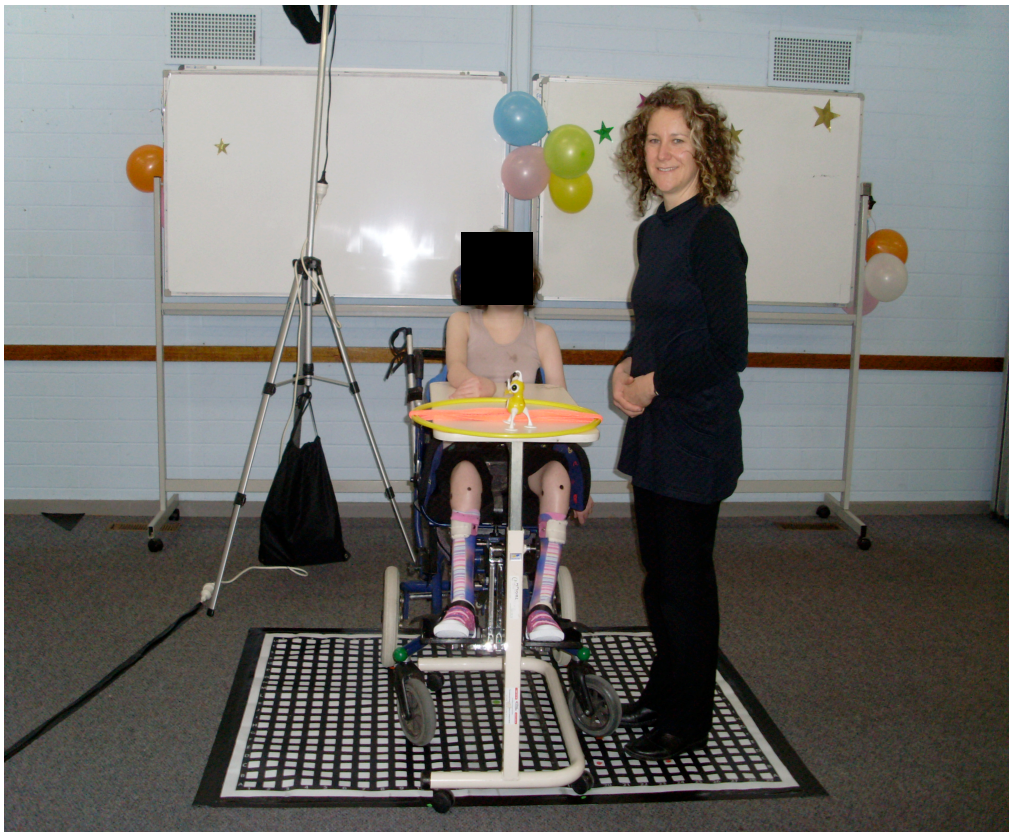


Plate 5.7 Filming: A) Trial filming - front, side and overhead views of child hopping across the grid; overhead camera not rotated correctly; B) Filming commencement.

5.3.5.2 ‘The Magic Room’ film set up

Two to three hours were planned for completion of the room set up, which was then left ‘in situ’ for a subsequent day’s filming. This set up included the decorations, grid, tripods and cameras set up as described above.

5.3.5.3 Individual film requirements

The individual film requirements for each child were then set up by the researcher. This included the side camera being placed at the left or right, the three tapes were marked with the child’s code and view (‘front’, ‘side’, or’ ‘overhead’) and placed in the three cameras, and then the child’s code filmed with the front camera.

5.3.5.4 Filming each child

The filming process followed the procedures developed for Pilot Study Two. When the child was ready on the set, the three cameras (waiting in ‘record mode’) were activated by the researcher using a remote control, to ensure the tapes were running and simultaneously recording for at least three seconds prior to ‘action’. The researcher indicated when all cameras were ready to capture the child’s performance, by giving a ‘silent nod’ (Plate 5.6a). The child’s performance was initiated with a verbal ‘go’ from research assistant one (the signal for start), and then a ‘cough’ from the research assistant (the signal for finish), for each of three consecutive trials of the child’s daily task / goal. Audible ‘marking’ of the start and finish of performance on the tapes was important for the editing stage.

Occasionally, a trial needed to be re-filmed; for example, if a child was crying, and the cameras were left running if there was any doubt. Communication between the researcher and assistant was quiet and brief in these circumstances. Following completion, the child was assisted to leave the film set and return to the waiting area and family. The overhead camera then recorded the dots on the floor grid for replicating positions on the grid.

5.3.5.5 Role of filming assistant

The purpose of using research assistants during filming was to enhance the speed of set up, and the reliability of visual data collected. While the researcher prepared the cameras for each child, assistance with filming was utilized to speed up the setting up process, including application of ink dots to precise anatomical landmarks (assistant one), and to prepare the film set according to the researcher's requirements (Plate 5.8 a-c). To ensure these conditions remained constant from pre-test to post-test and follow-up, assistant two checked that conditions had been recorded on the laminated grid, and through photographic records using a 'still' camera. Research assistant one also provided assistance with a child or with equipment on the set when this was required (Plate 5.9 a- c).

A 

B 

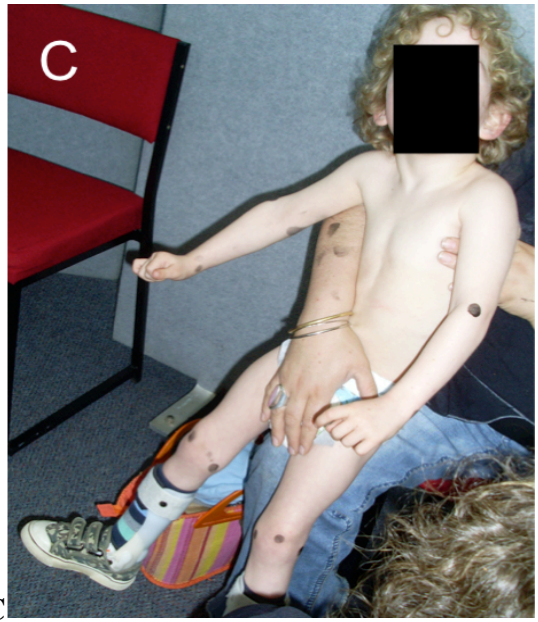
C 

Plate 5.8: Preparation of children for filming. A) Ink dot kit; B) and C) Application of the ink dots.

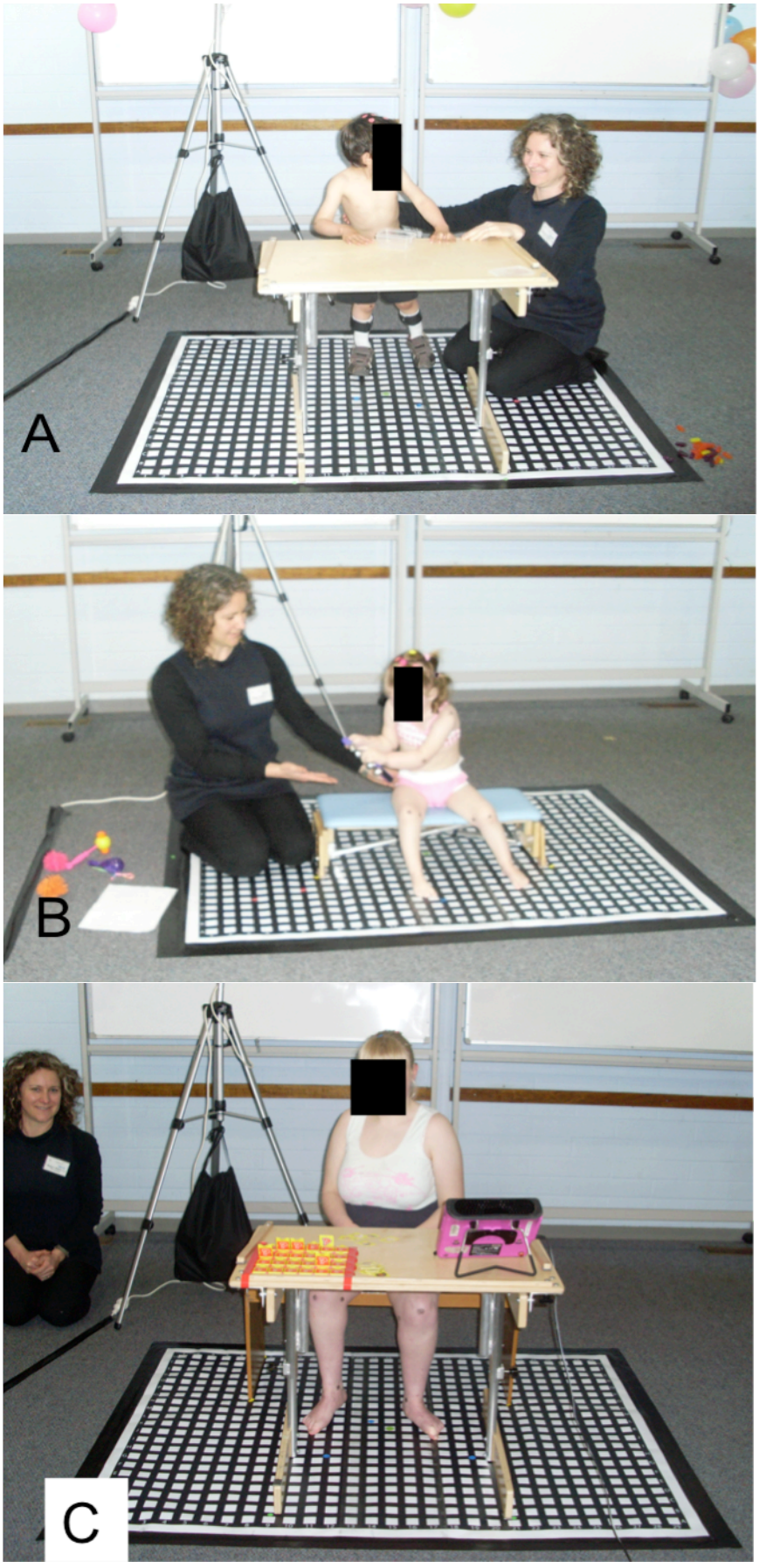


Plate 5.9 A - C: On set filming.

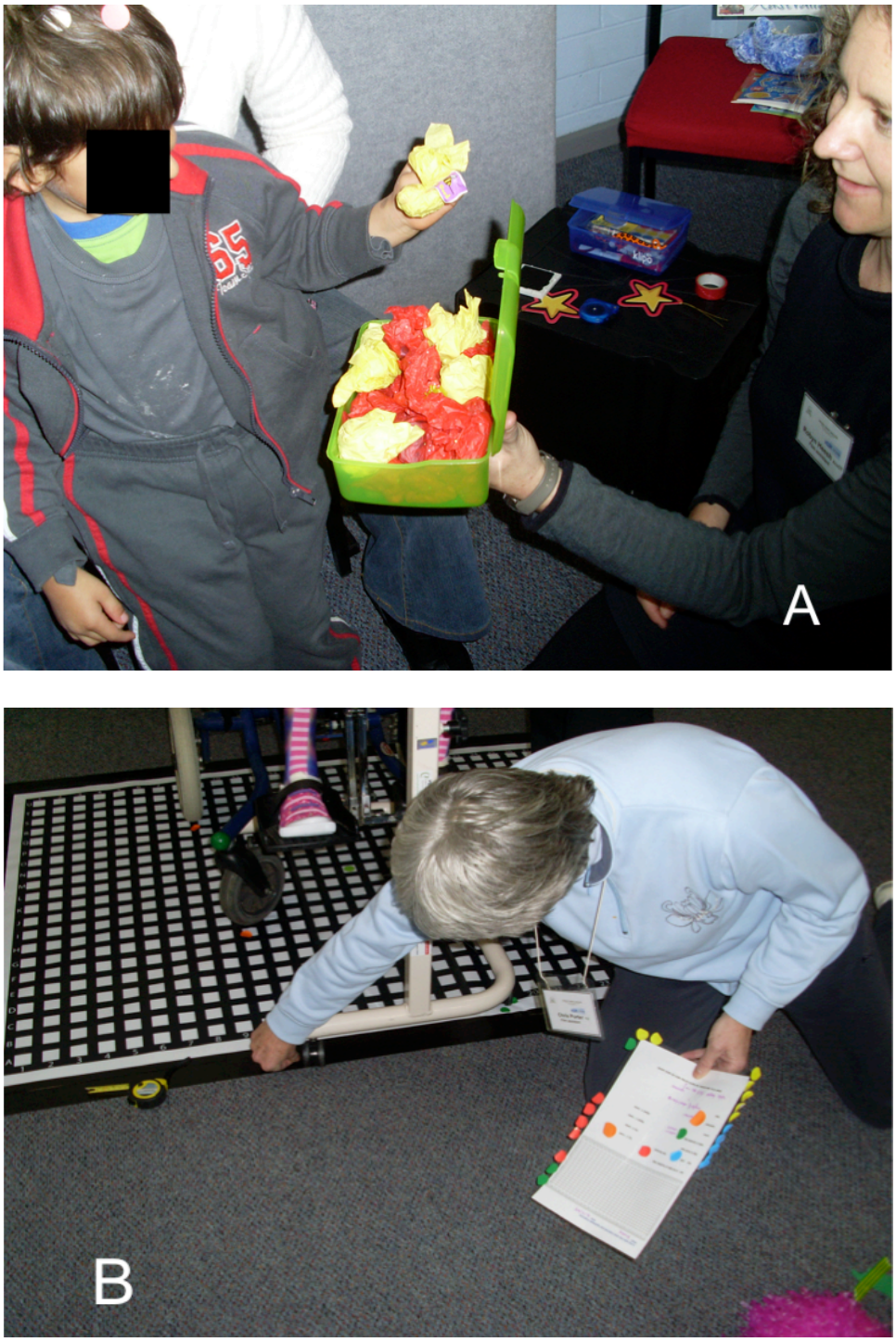


Plate 5.10: Aspects of the filming process. A) Choosing 'lucky dips'; B) Placement of colour-coded 'position dots' on the grid.

5.3.6 Editing

The video footage captured between the end of the 'go' cue and from the beginning of the 'cough' in each child's three trials was edited for all three pre-, post- and follow-up performance trials. The instruments used in editing video footage, and then for creating the DVD's, were described above.

All three trials of each pre-test, post-test and follow-up were carefully reviewed and the *best, completed trial* was chosen and edited from each performance. The three views of this performance (from front, side and overhead cameras; Plate 5.2 a-f.) were then edited to simultaneously 'play, repeat and slow play' on the same screen. The zoom function was used in editing for a closer view, for example, of children's hands, as depicted in Plates 5.3a and 5.3f. As this view at times resulted in pictures with less clarity, the original film footage was kept for on screen measurements with correct and relative measurements. The three final edited views of goal performances were then burnt to DVD format.

5.3.7 Independent rater GAS scores

Included in each DVD case were viewing and scoring instructions, with the appropriate GAS score sheet for each child. The DVD's (of unidentified pre-, post, or follow-up footage) were then randomly assigned and sent to the seven NDTA™ Coordinator Instructors who were blinded to the stage of intervention and who had consented to participate in this final phase of the research.

The randomisation process included ensuring that the CI's received no more than one of pre-, post- and follow-up DVD per child. Randomisation also included an

attempt to assign a 'similar' number of subscales to each CI for scoring, as subscale numbers per child varied from two to four. The range of number of children per CI was between four and seven and the number of subscales was fourteen to twenty.

As with Pilot Studies One and Two, CIs were asked to tick the one GAS statement which they judged to match the video footage they observed. They were also requested to check that they had correctly included either a 'plus' or a 'minus' sign preceding their score. The CIs returned their ratings and the DVDs to the researcher. A CD was made of the same material for each parent in gratitude for their participation.

5.3.8 Researcher generated GAS scores

As described in Section 5.3.2, the researcher constructed the GAS scales and sub-scales for each child, locating the pre-test performance at -2.0, and the desired goal behaviour at 0. After construction of the children's performances to DVD, the researcher used the same visual data that was allocated to the CIs to score the children's performance at post-test and follow-up. As with the instruction given to the CIs, the researcher judged the level of GAS which best described the children's subscale performance. The researcher scored all subscales of all the children on the appropriate GAS score sheets.

5.4 DESCRIPTION OF NEURO-DEVELOPMENT TREATMENT

5.4.1 Treatment description

The children received two hours of individual NDT twice weekly, generally with two therapists 'co-treating'. In addition, they each received three hours of assessment, goal setting and final post-treatment evaluation. Thus each child received 23 hours of treatment over a five week treatment block (Figure 5.11 a-c).

The therapists each treated two of the twelve children for over 40 hours of treatment practicum as required by the NDTA™. NDTA™ Instructors that supervised intervention included the Coordinator Instructor, a physical therapist, an occupational therapist, and a speech and language pathologist.

NDT treatment strategies were defined and taught by the Instructors during the course. This occurred during practical 'lab' sessions, through observation of and participation in treatment sessions, documentation in written assignments and through assigned readings.

Plate 5.11 a – c: Examples of NDT co-treatment. The children all received bi-weekly NDT

Accurate details of the NDT treatment strategies that the therapists employed were accessed from the therapists' written assignments and notes by the researcher, with permission from the participants. Each child had a different configuration of intervention strategies applied, which is in keeping with the NDT approach. A sample of the NDT intervention is recorded in Table 5.11 (and Appendices XXXI Tables a & b). The latter tables are presented in original form, derived from therapists' assignments and describe, in part, exactly what the therapists 'did', in terms of 'current NDT', in relation to the goals of two childrens. Consent to include these data was given by the therapists involved.

During NDT courses, therapists learn to 'administer' many different treatments strategies, and the criteria for their use. Of more relevance to this study, they also learn to apply these to individual and 'combined' body segments, and to specific task performance with individual children through:

1) Task analysis and goal setting relative to participation restrictions and functional limitations that are unique to each child.
2) Observing for consistency of atypically performed task related postural and movement behaviours.
3) Identifying and measuring the underlying associated system based impairments related to these behaviours.
4) Devising a treatment plan.

Examples of these processes are indicated in the information obtained from therapist assignments. Data for two children (Child 1 and Child 2) are displayed in Table 5.11. Examples of five common NDT treatment strategies (as

documented in the literature review in Chapter Two) are listed in column three of this table. In the fourth column, similar treatment strategies used for the four children, are indicated with a 'treatment strategy number'. This Table demonstrates that although there may be commonality among NDT treatment strategies, the application of strategies is highly specific and complex.

Table 5.11: Description of NDT treatment strategies used.

Description of NDT treatment strategies used:			
Child	**Goal of NDT intervention**	**Examples of NDT Strategies**	**Listed treatment strategies that are applicable for goals: child 1 & 2.**
Child 1.	**Donning socks**	1. Elongation of muscle groups / soft tissue for joint alignment 2. Facilitation of weight shifting such as required in transitional movements 3. Strengthening of hip and knee extensors e.g. for stepping. 4. Traction and vibration through the ribcage e.g. to increase respiratory volume for breath control 5. Stimulation techniques e.g. to improve head raising and vision for 'looking play', e.g. through linear vestibular movement	**NDT Treatment strategy 1, 2, 3, 5**
Child 2.	**Standing at a table to use hands**		**NDT Treatment strategy 1, 2, 4. 5**

NDT treatment strategies that were developed to address the children's goals in this study were applied with consideration not only for the overall functional and motor difficulties experienced by the child, but also with consideration for salient

events at the time of application, including things such as: temperament and emotional impact on tone (or stiffness) and motor function, motivation, sensory input, parental input, changes in physical and verbal prompts. Table 5.11 serves as an illustration of the complexity and individual nature of NDT treatment, rather than a complete example of intervention given by the therapist participants. Additionally, it serves as a record of the fidelity of NDT strategies that were applied in this particular research study (Appendix XXX1 a & b).

5.4.2 Role of the researcher in the NDT course

In this pilot study, the researcher not only carried out components of the study as described above, but also participated in the NDT course as an instructor, assisting with practicums and teaching NDT theory and strategy application. During the course practicums, her primary role was that of instructor, and the lesser role was that of researcher. These dual roles were established with the informed consent of the parents and therapists involved. While this study was not an in-depth qualitative study utilizing participation observation strategies as the data gathering tool, the researcher, in her role as instructor, was able to engage in continuous observation of actions and reactions of children, therapists and parents to NDT intervention, both planned and spontaneous.

The opportunity for in-depth observation over time in an instructor role contributed to an understanding of the children and their response to NDT, and enhanced the development of detailed and relevant GAS scoring sheets, and interpretation of data obtained through the research instruments outlined above. However, ongoing observation may also contribute to researcher bias in scoring of

the same research data. To control for this bias, the following strategies were put in place:

a) GAS scoring sheets were sent in random allocation to independent raters who were blinded to the stage of intervention and performance (pre-test, post-test and follow-up). Results from the researcher and the blinded raters were compared and bias was considered in interpretation.
b) Data collection (filming, parent questionnaires) was carried out at a different location and at a different time to that of the NDT course and did not involve therapist participants or other NDT instructors, thus separating the research procedures from NDT intervention procedures.
c) All other NDT instructors, including the Chief Instructor, were not participants in the study.
d) Information obtained from the course for use in the study (therapist reports, instructor reports, parent questionnaires) were utilized as secondary data which were obtained with the Chief Instructor's permission, and parent/therapist consent only at the completion of the course.

5.4.3 Outside therapies

Nine of the 12 children received additional 'outside therapy' during the course of the research. This included hand and foot orthoses, regular physiotherapy, speech therapy and occupational therapy, wearing of TheraTogs, hydrotherapy, dancing and swimming (See Appendix XXVIIii). While this may have contributed to goal attainment as measured in this study, they are not considered to be confounding issues to the results. All the therapies listed, except for one, described below were

ongoing therapies, instituted before the onset of NDT, and continued during the period of NDT withdrawal. The exception to this is Child 12, who received both NDT *and* Botulinum Toxin-A to lower extremities and an increase in spasticity medication (Baclofen) after pre-test filming. This was initially considered to be a confounding variable to making any association between NDT and the functional goal outcomes of standing independently and using hands to eat (See Table 5.13). Eliminating these data from subsequent statistical analysis did not change the significance of changes demonstrated by the group as a whole, therefore this child's data were kept in the subsequent statistical analyses described in the next section (5.5).

5.5 DATA ANALYSIS AND RESULTS

The first research sub-question that guided this phase of the researcher was: *"What is the change in children's functional performance in targeted daily living tasks immediately following NDT and at a follow-up period"?* In response to this question, the following results were obtained.

5.5.1 Outcome of NDT as measured by Goal Attainment Scaling

5.5.1.1 Description of changes in GAS scores between pre-test and follow-up.

The first analysis comprised a simple description of goal progress of the children as a group throughout the course of the study from pre-test to follow-up. In total, there were 14 goals generated for the 12 children in the study. This generated 57 filmed performances comprising front, side and overhead simultaneous views of best of three attempts at task performance at each of the pre-test, post-test and follow-up. Combined post-test and follow-up performance GAS scores utilizing

data from the researcher's scores were used to identify overall outcomes to the intervention. Table 5.12 shows the progress made towards desired goal attainment (0.0) during the course of the whole study using the GAS scores from -2 to +2. This table 'counts only the best of either post-test *or* follow-up results. (See Appendix XXXII for the table of post-test and follow up results separated.)

Forty two percent of performances filmed at post-test and follow-up were achieved at or above goal level (GAS 0 - +2), while 58% of task performances filmed at the same time did not reach goal level (GAS -1 or -2).

When *progress towards the desired goal* or better was calculated, 89% of goal performances filmed at post-test and/or follow-up showed positive change toward or above goal level from pre-test performances (any progress above -1), while 10.5% showed no change. (GAS remained at level -2).

Table 5.12: Description of changes in GAS scores between pre-test and follow-up.

DESCRIPTION OF GAS LEVEL	LEVEL	NUMBER OF SUBSCALES SCORED AT POST-TEST OR FOLLOW-UP
Much more than expected	+2	6 (6 post-tests & follow-ups combined scored at this level)
Somewhat more than expected	+1	4 4 post-tests & follow-ups combined scored at this level)
Goal achieved	0 (goal)	14 (14 post-tests & follow-ups combined scored at this level)
Progress made towards goal achievement	-1	27 (27 post-tests & follow-ups combined scored at this level)
Baseline performance pre-NDT intervention	-2 (baseline)	6 (6 subscales showed no change at post-test or follow-up combined)

5.5.1.2 Visual analysis and results of pre-, post- and follow-up GAS scores

The standard GAS scores obtained from the researcher's analysis of each child's performance and the CI's analysis of children's performance were converted to T scores using the following formula example.

$$\text{GAS score} = 50 + \frac{10\Sigma(w_i x_i)}{\sqrt{(.7\Sigma w_i^{\,2}) + .3(\Sigma w_i)^2}}$$

In this formula, if all goals are achieved (i.e., final score of "0" for each), the final summated score derived from this formula will be 50. If, on average, the sub-goals are overachieved (i.e., scores at the +1 or +2 level), the final summated score will be greater than 50. Conversely, a final score of less than 50 will represent a shortfall in achievement. 'W' is the weighting given to the i^{th} goal and x_i is the level or numerical score (-2, -1, 0, +1, +2) of the i^{th} goal. Kiresuk, Smith and Carillo (1994) have provided tables from which the GAS t-score can be derived.

Figure 5.6 is a visual summary of mean GAS ratings between baseline, post-test and follow-up for the researcher and for the CI raters. All mean GAS scores are less than 50, indicating that, on average, sub-goals were underachieved at baseline, post-test and at follow-up. Inspection of the individual scores (see Table 5.13) reveals that only 16 of the 42 CI rater post-test scores were at or above the goal level, for example. However, the graph does indicate an increase in mean GAS scores from baseline to post-test.

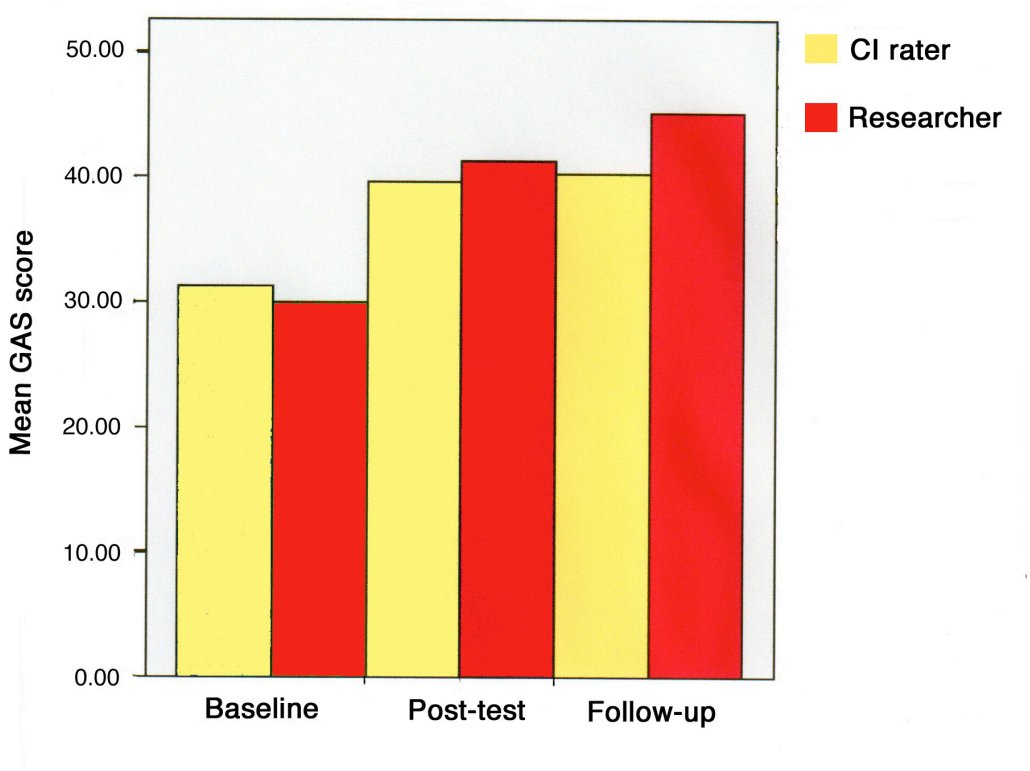


Figure 5.6: Comparison of researcher and CI rater mean GAS scores at baseline, post-test and follow- up. CI = Coordinator Instructor. Mean GAS score (y-axis) refers to the mean GAS conversion score.

As indicated in Figure 5.6, the mean GAS conversion scores at pre-test, post-test and follow-up indicated a marked improvement between pre-test to post-test as judged by both researcher and CI raters. Differences in performance between post-test and follow-up, although visually apparent, were not as marked. There appeared to be a difference in judgment of the amount of difference noted between researcher and CI raters. The overall indication from this visual analysis was that the children's functional performance, as measured by GAS continued to improve to the follow-up level.

A further breakdown of the overall GAS scores is shown in Table 5.13. This Table illustrates the progress towards goal attainment of each individual child through the course of the study from pre-test to post-test, and contributes further

detail to the visual analysis of progress of individual children. This Table illustrates change between pre-test and post-test only, as previous analyses indicated no significant difference between post-test and follow-up overall GAS scores.

In Table 5.13, a summary of the overall goal is stated in column one; the GAS subscale number is stated in column two; and the subscale GAS scores derived by the research and CIs are stated in the following four columns. As can be seen from the table, the greater proportion of children's GAS sub scale scores moved in the direction towards attaining goals, however, the change made was variable, with some children making less gains than others. Similarly, although the researcher and CIs were in general agreement with the direction of change, there was some difference in individual scores between the CIs and the researcher. No further statistical analysis was done on these individual subscale scores due to the small numbers of participants in the study.

Table 5.13: Researcher and CI rater GAS scores for each child pre- and post-test (and see Appendix XXXIII).

Child & Goal Area	Gas Subscale No.	Pre-test		Post-test	
		Researcher	CI	Researcher	CI
1. Movement forwards for assisted transfers from wheelchair.	1	-2	-2	-2	+1
	2	-2	-2	-1	+1
	3	-2	-2	-1	-2
	4	-2	-2	-1	0
2. Eating with a fork.	1	-2	-2	-1	+1
	2	-2	-2	-1	-2
3. Finger feeding.	1	-2	-2	-1	-2
	2	-2	-2	-1	-2
	3	-2	-2	-2	-1
	4	-2	-2	-1	-1
4. GOAL A. Reaching to grasp toys 'beyond her reach', at the side.	1	-2	-1	-2	-1
	2	-2	-2	-2	-2
	3	-2	-2	-1	-2
	4	-2	-2	-1	-2
4. GOAL B. Reaching to grasp toys 'beyond her reach' across midline.	1	-2	-2	-2	0
	2	-2	-2	-2	0
	3	-2	-2	-2	0
	4	-2	-1	+2	+1
5. Communicating using a Dynavox.	1	-2	-2	+2	+2
	2	-2	-2	0	0
	3	-2	-2	0	+2
6. Standing to use a bat.	1	-2	-2	-1	-2
	2	-2	-1	-1	-2
7. Executing 'Ronde de Jambe' ballet move (for ballet class).	1	-2	-1	-1	0
	2	-2	-1	-1	-1
	3	-2	-1	-2	0
	4	-2	-2	-1	-2
8. Undoing screw top lids.	1	-2	-2	+2	0
	2	-2	-1	-2	-2
9. GOAL A. Walking to throw a ball through a hoop.	1	-2	-2	-2	-2
	2	-2	-1	0	0
	3	-2	-1	-2	-2
9. GOAL B. Vocalising with clarity.	1	-2	-1	-1	-1
	2	-2	-2	-1	-2
10. Climbing a step to reach a toy.	1	-2	-2	0	-2
	2	-2	-2	+1	0
11. Donning socks.	1	-2	-2	-1	-1
	2	-2	-2	-2	-2
12. Standing at a table to use hands.	1	-2	-2	-2	-2
	2	-2	-2	-1	-1
	3	-2	-2	0	-1
	4	-2	-2	0	-1

5.5.1.3 Statistical Analysis

The visual analysis was followed up by statistical analysis of the same data to determine the significance of the differences between the three test conditions outlined in the visual graphs.

The converted GAS scores were also used for a Wilcoxon signed-rank test to determine the differences between performances (Appendix XXXIV). The Wilcoxon signed-rank test is a non-parametric equivalent to the parametric **t**-test for correlated samples when all or any of the following conditions exists, as found in this study:

1. The scale of measurement for test A (T_A) and test B (T_B) does not have the properties of an equal-interval scale.
2. The differences between the paired values of T_A and T_B have not been randomly drawn from the source population.
3. The source population from which these differences have been drawn does not reflect a normal distribution.

The Wilcoxon signed-rank test applies to two-sample designs involving repeated measures, matched pairs, or "before" and "after" measures. In this study, it is used to reflect the differences between one ordinal GAS score and another (pre-test and post-test: post-test and follow-up) (Portney & Watkins, 2000).

Results: Researcher GAS

Analysis of the *researcher scores* indicated significant difference between pre-test GAS scores and post-test GAS scores (p = .000). There were no significant differences between post-test GAS scores and follow-up GAS scores (p = .159).

Results: CI GAS

Analysis of the blinded CI rater scores indicated significant differences between pre-test baseline GAS scores and post-test GAS scores (p = .001), and no significant difference between post-test GAS scores and follow-up GAS scores (p = .978).

These results are summarised in Table 5.14 and support the results of the visual analysis, which show significantly improved performance between pre-test and post-test performance in the mean scores of the twelve children.

Table 5. 14: Change as recorded on the GAS scales by Researcher and CI raters - following NDT for the 12 children.

	Baseline to post-test	**Baseline to follow-up**	**Post-test to follow-up**
Researcher	p = .000 *Highly significant*	p = .000 *Highly significant*	p = .159 *No significant difference*
CI Raters	p = . 001 *Highly significant*	p = .000 *Highly significant*	p = .978 *No significant difference*

5.5.1.4 CI and researcher inter-rater reliability

The data generated by the CI blinded rater scoring was further compared to the researcher's scores by comparing their mean GAS scores using Cohen's kappa coefficient (κ). Cohen's kappa coefficient is a measure of inter-rater agreement for categorical items such as the GAS scale (Portney & Watkins, 2000). It is generally thought to be a more robust measure than simple percent agreement calculation since κ takes into account the agreement occurring by chance. This analysis resulted in Kappa = 0.32, indicating 'fair agreement' between CI and researcher means GAS ratings as a whole (Appendix XXXV).

A limitation of the Kappa, however, is that it is an analysis of exact agreement between raters (Portney & Watkins, 2000). GAS scaling for NDT outcome data requires intricate scaling according to subtle differentiation in changes in posture and movement behaviours between each GAS level. In this study, the researcher GAS score was derived from opportunities to view children's live performance, while CI blinded raters viewed taped performance only. It could be argued that exact agreement between the researcher and CIs could have been influenced by this difference, and that perhaps CI scores that *closely approximated* the researcher scores by one GAS level may be clinically significant. Of the 115 measurement points rated by the CIs, the majority of the scores (101) were within one GAS score difference, while 14 scores demonstrated a larger discrepancy. Consequently, Kappa was also utilized to calculate CI rater agreement within one point of the researcher. This result was Kappa = 0.42 (Table 5.15), a score that indicates 'moderate level agreement'. Calculation of a straight percentage of CI

raters' scores within one score of the researcher's score was performed, resulting in 87% agreement (Table 5.15).

Table 5.15: Summary chart of Kappa scores and percentage agreement for exact GAS score agreement, and for CI raters GAS scores within one point of the researcher's scores.

Kappa statistic for 100% agreeance of CI raters' scores with Researcher's scores	K= .32 (fair agreement)	Straight percentage of 100% agreeance of CI raters' scores with Researcher's scores	56%
Kappa statistic for CI raters' scores within 1 score either side of Researcher's scores	K = .42 (moderate agreement)	Straight percentage of CI raters' scores within 1 score either side of Researcher's scores	87%

Computing separate Kappas for pairs of raters is thought to be more informative than with more than two raters (Portney & Watkins, 2000). Therefore, separate Kappas were calculated for each CI rater with the researcher on the basis of their mean GAS subscale scores (Table 5.16)

Table 5.16: Individual Kappas calculated for each CI and Researcher

CI RATER	INDIVIDUAL KAPPA	DESCRIPTION
Rater 1.	.72	Substantial level of agreement
Rater 2.	.64	Substantial level of agreement
Rater 3	.56	Moderate agreement
Rater 4.	.88	Excellent agreement
Rater 5.	.4	Moderate agreement
Rater 6	.64	Substantial level of agreement
Rater 7.	.97	Excellent agreement

Results indicated that five of the CI raters were in 'substantial ' to 'excellent' agreement with the researcher, while two demonstrated moderate agreement with the researcher's scores.

Comments that the CIs offered in emails to the researcher in their return emails indicated areas of difficulty they experienced in judging children's performance using DVD and GAS scales derived for this study. These comments may contribute to explanations about reduced agreement between some CI and researcher scores. Comments are summarized in Table 5.17.

Table 5.17: Summary of CI's (Coordinator Instructors) comments related to the GAS scales

Comments related to scoring	Comments related to GAS scales
2 CI's commented on difficulty in seeing a component clearly enough for scoring such as: "Extremely difficult to see most abducted point" (Lower extremity / dance step) (CI^2) One commented that the scoring for a particular subscale was "very difficult" and added that " . .but all of them were difficult to an extent". (CI^6) *In addition:* "I had a really hard time and feel that I can't judge well at all with a 2 second video" (CI^6). (This video footage had not correctly converted to DVD. It was remade & resent for scoring.) ". . made me look very carefully" (CI^1) I CI had difficulty opening the DVD's (CI^4)	*The following are comments about the nomenclature used in the subscales:* Referring to 'arm' not 'hand' (CI^1); using words 'upright' or 'neutral' pelvis in same subscale (CI^1) "I could not differentiate the scoring descriptor for -1 & -2" (CI^2) (they were in fact the same) The trunk elongation' side' with reach to right or left side was written incorrectly. (CI^3)

5.5.2 Outcomes as measured by Logger Pro / Excel

The use of Logger Pro with Excel resulted in 'home computer' based measurements of a number of parameters of targeted goal behaviours. One change in a goal-related parameter was analysed for each child (Examples in Appendix XXXVI i – v). The error of measurement was *'estimated'* to be 1% to 2%; and up to 5% (by research assistant three) if the ink dots applied to child's anatomical landmarks were obscured in any way. These estimates are consistent with those of Hough and Hughes (2006), who measured goniometric range of movement from onscreen video footage, and to the very early suggestions of the

use of computerized motion analysis video software, as recorded in Chapter Two, as the 'best measurement tool' of subtle physical changes following NDT (De Gangi, Hurley, & Linscheid, 1983; Lilly & Powell, 1990).

Table 5.18 represents a summary of the results from data analysis to quantify descriptive changes in goal related *movement parameters*, such as timing, distance moved and range of movement. Changes are presented in full in Appendix XXXVII (Tables a and b).

Table 5.18: Results of the changes in distance, joint range, and timing of children's movements during task performance following NDT (post-test or follow-up) as measured by Logger Pro.

Child - code	CHANGE
1.	**92.3% increase** in total time head remains at partially in contact with headrest
2.	**78.3% decrease** in excessive trunk flexion when using a fork
3.	**6,800 mm^2 or 128.3% increase** in the expansion of hand opening in preparation to grasp 'biscuit' from the table.
4. Goal A	**69.6 % decrease** in time taken to grasp toy with left hand across midline
5.	**Left foot: 96.6% decrease in "excessive movement"** (amount of time that foot "moved excessively" on the surface (* with reference to given 'excessive movement" definition) See Appendix XXXVI. **Right foot: 95.6% decrease in "excessive movement"** (amount of time that foot "moved excessively" on the surface (* with reference to given 'excessive movement" definition See Appendix XXXVI, Table A.
6.	'Visually observable' improvement in counter rotation was not measurable as clothing obscured pelvis dot.
7.	**262mm or 108% increase** in the distance that the R. foot moved forward in ballet step
8.	**35% decrease** in time taken to unscrew the lid of drink bottle
9. Goal A	**78.8% decrease** in time the L. elbow flexed beyond 70 ° or more during lifting & releasing ball)
10.	**6.5% increase** in vertical orientation of upper body over pelvis & lower extremity of the ('more involved') R. stance leg while stepping.
11.	**69.6%** increase in present timed assistance of left hand in sock donning from pretest to follow up.
12	**100 %** increase in time standing independently at least 10 cm from the table edge during task performance.

5.6 Parent and therapist perceptions

The second research sub question addressed in this Pilot Study was: *"What were the parent and therapist perceptions of goal outcomes and related NDT intervention?"*

Comments from the course outcome surveys (Davis, 2008), which were completed by parents and therapists at the end of the NDT course, and the therapists' 'end-of-course' notes to parents were grouped according to the goal derived for each child, and briefly describe parents' and therapists' perceptions of goal outcomes. Written comments were summarized and tabulated.

5.6.1 Parents' perceptions of goal outcomes

Parents' comments regarding goal outcome behaviours were generally expressed more colloquially than were the therapist'. Some examples are: *"ability to get a sock on her foot;" "he has only had three falls in this time which compares to at least one a day before;" "he can talk louder;" and "seemed to stand tall."* However, one parent wrote: *"able to use her obliques now to coordinate rotating movements."* This latter example finds resonance with the researcher's experience that some parents like to understand, in full detail, the basis of the functional motor control their children are learning, and use 'therapist language' to express their observations.

Parents described how goal related behaviors were carried over to home when doing the same task that was targeted in therapy, such as: *"was able to calm himself down and focus on a task for longer"*; *"coming forward in her wheelchair*

more ; "he even stood with both feet flat of his own accord more often"; and *"has improved his ability to stand from sitting in a chair."*

Parents' comments reflected that they had observed generalized effects of therapy to other daily tasks. Examples included: *"he can now open jars and cut food without leaning"; "participating in activities that require more strength for longer periods of time"; "sitting and playing for longer periods"*; and*, "slept very well."*

Parents referred more often to the impact of therapy on their children's feelings than did the therapists. There were comments such as *"able to actively (and happy doing this) participate in activities that . ."*; and *"gained more confidence in completing her goal."*

Tables 5.19 summarises the comments from the Course Outcome Survey (Davis, 2008) from the parents relative to the degree to which they perceived children to have achieved the nominated goal.

Table 5.19: Parents' perceptions of goal outcomes (Davis, 2008)

Parents' perceptions of goal outcomes (Davis, 2008)	
Child's goal	**Parent comments in response to the question in the NDT course parent questionnaire : "Did your child make any functional gains during this NDT course"?**
1. Movement forwards for assisted transfers from wheelchair.	• "Improvement in trunk control, head control, eye gaze, jumping – rarely does – do this, but each night laying in bed she would do little jumps (I think they started at the shoulders and buttocks) and she cheekily smiled through these to show me she had some control over her body." • "She slept very well and it helped to clear phlegm from her throat (good coughs)." • She has also been coming forward in her wheelchair more."
2. Eating with a fork – with related postural control in sitting	• "He can talk louder." • "I think he has better trunk control"
3. Finger feeding – with related postural control in sitting	• "Yes I think – has gained a lot from the treatment course."
4. Goal A. Reaching to grasp toys 'beyond her reach', at the side – with related postural control 4. Goal B. Reaching to grasp toys 'beyond her reach' across midline – with related postural control	• "Yes – improved balance and coordination → increased core strength." • "We can hold her further down on her legs for standing now and she is more balanced and can maintain this balance for longer periods of time." • Able to use her obliques more to coordinate rotating movements – range of rotation has increased." • " Confidence has increased – she is now more willing (because she is more able) to move away from her centre." • " Able to actively (and happy doing this) participate in activities that require more strength for longer periods of time –"
5. Communicating using a Dynavox - with related postural control	• "Sentences on her 'Dynamite'." • "Better posture."
6. Hit a balloon with a bat - with related postural control for play in standing	• "Yes – was able to stand with both feet flat for an extended period of time." • "He even stood with both feet flat of his own accord more often."

Table 5.19 (continued)

7. Executing a 'Ronde de Jambe' ballet move (for ballet class) - with related in postural control lower extremity movement control	• "- seemed to stand tall and more central rotating and separating limbs and trunk making actions of movement more fluent."
8. Undoing the screw top lid of his water bottle – with related control in upright stance and bimanual skill	• "Yes, he can now open jars and cut food without as much leaning in his body." • "He has only had 3 falls in this time which is compares to at least one a day before."
9. GOAL A. Walking to throw a ball through a hoop with related postural and limb movement control - and 'regulatory',,control GOAL B. 'Steady' standing to blow out 3 candles - with related oral motor control	• "Yes, sitting and playing for longer periods." • "Was able to calm himself down and focus on a task for longer." – " for longer than 1 minute." • "Better lip rounding (blowing bubbles)."
10. Climbing a step to reach a toy with his right hand – with related postural control	• "Yes, much more stable in his movement."
11. Put on her right sock using both hands –with related postural control	• "- A little better posture and the ability to get a sock on her foot". • "- gained more confidence in completing her goal"
12. Standing at a table to use his hands	• He appears to be able to stand better (aided) with trunk control." • "Can stand leaning on a small table and play with one hand, while using the other to support himself." • Has improved his ability to stand from sitting position on a small chair."

In addition to the Course Outcome Survey, broader parent impressions of the impact of the course on families and children was captured by using a modified version of the Measures Of Processes Of Care (King, Rosenbaum, & King, 1995). Parent responses were summed and percentages of responses indicating "more than sometimes" (scores 5-7) or "sometimes or less" (scores 1-4) are displayed in Table 5. 20. Generally, the results revealed that the needs of the parents during the NDT course were being met, with 100% of parents nominating 'more than sometimes' (scores 5 - 7) for 12 of the 20 questions, and over 90% of parents nominating 'more than sometimes' (scores 5 - 7) for 17 of the 20 question.

Table 5.20: MPOC alternative scoring table (King, Rosenbaum, & King, 1995a)

Percent replying "more than sometimes" (scores 5-7)		**Percent replying "sometimes or less" (scores 1-4)**	
Q. No.	**"IN THE PAST . .*6 WEEKS*. . TO WHAT EXTENT *DID THE THERAPISTS* WHO WORKED WITH YOUR CHILD . . "**	**TOTAL % replying "more than sometimes" (scores 5-7)**	**TOTAL % replying "less than sometimes" (scores1-4)**
3.*	". . .offer you positive feedback or encouragement" *(e.g. deleted)*	**81.8%**	**18.2%**
4.	" . . .explain things to your child in a way your child understands"?	**91.7**	**8.3%**
5.	" . . . take the time to establish rapport with you or your child" *(final words deleted)*	**91.7%**	**8.3%**
6.	" . . . discuss with you . . .*your family's goals and* . . . expectations for your child, so that all agree *(final words deleted)*	**83.3%**	**16.7%**
9.*	" . . .accept you and your family in a non judgmental way"?	**100.0%**	**0%**
11.	" . . .recognise the demands of caring for a child with special needs"?	**100.0%**	**0%**
12.	" . . .trust you as the "expert" on your child"?	**100.0%**	**0%**

Table 5.20 (continued)

13.	". . . look at the needs of your "whole" child *(e.g. at emotional and mental needs*) instead of just at physical needs"?	**100.0%**	**0%**
14.	*[If applicable]* " . . .show sensitivity to your family's feelings about having a child with special needs)e.g. your worries about your child's health or function)"?	**100.0%**	**0%**
16.	". . . make sure you have a chance during visits to the centre to say what is important to you"?	**99.9%**	**.1%**
18.	". . .remember personal details about your child or family when speaking with you" . *or your child?*	**100.0%**	**0%**
19.	". . . tell you about the reasons for treatment"? *(final words deleted)*	**62.2%** ***	**37.8%** ***
23. *	". . . answer your questions . ." *within the confines of the NDT course?*	**100.0%**	**0%**
29. *	". . . provide a caring atmosphere rather than just give you information"?	**100.0%**	**0%**
31.	". . . treat you as an individual rather than as a "typical" parent of a child with a disability"?	**100.0%**	**0%**
32.	". . . develop both short term and long-term goals for your child"?	**100.0%**	**0%**
33.	". . . treat you as an equal rather than just as the parent of a patient"? *(final words deleted)*	**91.7%**	**8.3%**
35.	' . . .make sure you have opportunities to explain what you think are important treatment goals"?	**100.0%**	**0%**
36.	". . . Make you feel like a partner in your child's care"?	**91.7%**	**8.3%**
42.	". . . treat you and your family as people rather than as a "case" (e.g. by not referring to you by diagnosis, such as "the spastic diplegic")"?	**100.0%**	**0%**

5.6.2. Therapist perceptions of goal outcomes

In comparison to parents, therapists more often reported detailed lists of body system-based improvements in goal related outcomes (Table 5.21). For example, referring to types of muscle contractions and actions: *"initiate", "eccentric", "rotation"*, or *"range of movement";* or more complex statements such as *" initiation of reach with right upper limb took greater than two minutes initially (sic) . . this reduced to 30 seconds"; "he accepted more tactile and proprioceptive input to his foot"; "spontaneous lip closure and swallowing of saliva"; "better able to grade arm movements for targeted reach".* The therapists' comments were expressed more colloquially in reports to parents, such as *"he can walk up and down stairs with less leaning to his left side."*

Therapists frequently referred to outcomes as they contributed to a broader functional framework than one specific task. For example, a child was described as "*(child) is using longer sentences when communicating (combining two and three words);" "he can follow / find toys with his eyes / head, to name choices / play;" " he was able to change his body position with a verbal cue 'get your feet ready and flat',"* or, *"she became quicker in using her eyes for communication and for visually guided reach."*

Table 5.21: Therapists' perceptions of goal outcomes (Davis, 2008)

Therapists' perceptions of goal outcomes (Davis, 2008)	
Child's goal	**Therapists' recorded comments on goal related progress to parents - and in response to the question in the 'Therapist NDT course evaluation questionnaires': "Did the child(ren) who participated in the course treatment practicums / demos etc make any functional gains during this NDT course?"**
1. Movement forwards for assisted transfers from wheelchair.	• " – became more relaxed while remaining alert and engaged socially. She used less effort to sustain upright sitting with support and could stay longer without becoming overtired and needing to lie down, or begin to push into extension in an effort to remain upright." • " – was able to increase her initiation with reaching (with) right upper limb. In the beginning we had to wait up to >2 minutes for – to begin a small movement; at the end she could initiate the movement with only a slight delay following request <30 seconds." • " - decreased her turning and pushing back posture in sitting and transitions, so that she could keep her head more in the middle of her body as we were helping her move between postures, with less biting or catching on her lip." • " – she became quicker in using her eyes for communication and for visually guided hand function."
2. Eating with a fork – with related postural control in sitting	• "He is sitting up straighter with less help." • "He can reach further forward, without bending his trunk forward, to reach his toys." • "He can follow / find toys with his eyes / head to name choices / play." • "He can sit on mat with mid support on the trunk and attempt" • "Increased weightbearing" – hands"
3. Finger feeding – with related postural control in sitting	• "She is able to sit up taller with less pushing backwards when reaching for toy." • She sat up . (tailor sitting) . . without support for 25 – 30 seconds." • "She is indicating her choice of toys more now." • "She is able to reach for toy with support (moderate) at T12/L1 level and her elbow (supporting) • "She is helping in transition movements (- from sit to side sit to crawl position.") • "We are able to facilitate a few steps of crawling." • "She pushes up on her right arm to help in the transition above and also to support herself during play in high kneel position." • " – has got more head control."
4. Goal A. Reaching to grasp toys 'beyond her reach', at the side – with related postural control 4. Goal B. Reaching to grasp toys 'beyond her reach' across midline – with related postural control	• "She has shown improvement in her active range of reach in terms of reaching to the side and diagonally." • "She was able to maintain a more alert state, better regulated in terms of less crying or fussing."

Table 5.21 (continued)

5. Communicating using a Dynavox - with related postural control	• "Increased reaching in a variety of directions with rotation for 'dancing'." • "Using longer sentences when communicating (combining 2 and 3 words)." • "Spontaneous lip closure and swallowing of saliva." • "Unsure how much has been generalised outside session."
6. Hit a balloon with a bat - with related postural control for play in standing	• " He was able to keep his right heel down for standing for a longer period of time." • "Still has difficulty with dynamic movements." • "Less stiffness in his lower limbs."
7. Executing a 'Ronde de Jambe' ballet move (for ballet class) - with related in postural control lower extremity movement control	• " - is beginning to increase the amount of weight she takes on her right leg." • "She is also beginning to move her legs in different directions at the same time." • " – is beginning to bring her left heel down to the ground on occasion when walking." • "- is beginning to show increased range of movement in her legs → she is able to turn them outwards more." • "Increased balance and control in single leg stance." • "Increased hamstring (eccentric) control." • "Increased confidence in her own body."
8. Undoing the screw top lid of his water bottle – with related control in upright stance and bimanual skill	• "Better able to move one body part over another ie he can turn his trunk and upper body while keeping his pelvis facing straight ahead." • ''Taller posture" • "Able to open the jar full of water with the right amount of tone - not too much, not too little." • "Became more aware of muscles required for movements – active abs, hip abductors."
9. GOAL A. Walking to throw a ball through a hoop with related postural and limb movement control - and 'regulatory',,control GOAL B. 'Steady' standing to blow out 3 candles - with related oral motor control	• " – was able to calm himself down and focus on a task for a longer time." • " We were able to make changes in his foot alignment, but carryover to the next session was a little poor." • " – kept his foot on the ground (left > right) for greater number of steps." • " – able to blow bubbles for longer and get better lip rounding."
10. Climbing a step to reach a toy with his right hand – with related postural control	• "- stayed focussed on activities that he liked to play!" • "He could take more weight on his right foot as he moved; 'keep' his foot flat on the floor." • "He is able to change his body position with a verbal cue 'get your feet ready and flat'." • "He accepted more tactile and proprioceptive input to foot." • "More tolerance to handling, calmer – better able to regulate his arousal level with introduction of 'sensory breaks." • "He can walk up and down stairs with less leaning towards his left side, having less assistance and he walks down with less wobbling over his right leg." • "More willing to use his right hand." • "He can reach out with his right hand with greater excursion while – balance in standing." • " He has more stability during stairs walking."

Table 5.21 (continued)

11. Put on her right sock using both hands –with related postural control	• " -is starting to use both hands more readily without prompting and is becoming more independent in taking her shoes / socks off and unzipping her jacket" • " It now takes her a lot less effort and time to do these activities!" • " Uses her left hand so much more in shoes/socks on and off" • " Decreased time taken to complete tasks." • " Increased time to 'problem solve left hand."
12. Standing at a table to use his hands	• "- can stand better and he can now use his right hand to play in standing." • "He can stand up independently from sitting on a chair and play a game in standing." • "Better able to regulate his arousal level." • –" and helped - in- positive changes, like better transition from sit to stand - and - standing activities " • "Learned to reciprocal crawl 'far' effectively." • "Better able to grade arm movements for targeted reach." • "- would take less time to do the task now."

These qualitative descriptive excerpts from the surveys, illustrate how parents and therapists expressed goal achievements and attributed a broader meaning to the achievement, by linking it to other everyday life tasks. This qualitative data, although only a small aspect of this study, contributes to the quantitative Goal Attainment Scaling results outlined above by further describing perceptions of the impact of NDT on the daily task performances of the children.

5.7 SUMMARY OF RESULTS AND OUTCOMES

The following findings relate to the research sub questions for Phase Four, Pilot Study Three:

i. "What is the change in children's functional performance in targeted daily living tasks immediately following NDT and at a follow up period?"

ii. "What were the parent and therapist perceptions of goal outcomes and related NDT intervention

Finding 5.7.1

Significant change was found in children's functional performance of goals related tasks, as measured by GAS scales by both the researcher and the 'blinded' CI raters, from baseline to post-test (Table 5.14).

Finding 5.7.2

Although performance improvement from post-test to follow up was not found to be statistically significant, functional ability was maintained over the six week follow up period when intervention was withdrawn (Table 5.14).

Finding 5.7.3

Inter-rater reliability between GAS scores derived by the researcher and individual CI raters, blinded to the condition of intervention, showed 'substantial to excellent agreement' between five of the expert blinded raters with the researcher, and moderate agreement between the researcher and two CIs. Comparison between mean researcher and CI GAS scores was 'fair'. Straight percentage agreement of GAS subscale scores within one point of researcher was 87% with 57% for exact agreement.

Finding 5.7.4

Further video motion analysis with Logger Pro resulted in details of movement parameters that appear to be related to positive changes in GAS scores obtained by the children. These included changes in postural alignment, time taken to move during task performance, distance moved, hand expansion for grasp and communication.

Finding 5.7.5

In the qualitative outcome measures of the independent variable, the Measures Of Processes Of Care results suggest parents perceived NDT as supporting family centred practice. Similarly, the narrative from both parents and therapists relating to the children's goal outcomes and their experiences with NDT, were found to be positive.

Finding 5.7.6

In an attempt to control for other potential variables for functional change by the children, parents were surveyed for simultaneous 'outside therapies', and one child did have a potentially 'influencing' change in spasticity management (Appendix XXVIIii).

In addition, the filming protocol was further developed, particularly in methods to ensure replication from pre- to post- to follow-up filming. It is suggested that the 'controlled' 'NDT measurement model', which was further developed through Pilot Study Three, was more sensitive and accurate and therefore was better able to detect changes in functional performance.