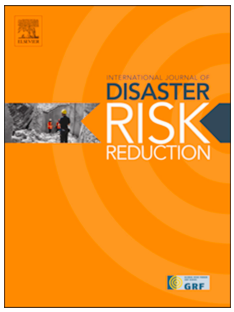

Silent no more: Identifying and breaking through the barriers that d/Deaf people face in responding to hazards and disasters

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Silent no more: Identifying and breaking through the barriers that d/Deaf people face in responding to hazards and disasters

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Abstract

The Sendai Framework for Disaster Risk Reduction (2015-2030) mandates stronger inclusion of persons with disability in DRR. Yet pathways to achieving new targets for disability-inclusive disaster risk reduction (DiDRR) and their feasibility remain unclear and are under-researched. To redress this gap, we undertake a three-step longitudinal assessment that: examines the challenges the d/Deaf community, a cultural and linguistic minority with an invisible disability, in New South Wales, Australia face in accessing the support they need to effectively respond to risk; presents a range of community-driven resilience-building solutions that derived from the research; and most critically (iii) follows the implementation and outcomes of key resilience building solutions over a 6-year period and the impact these 'system feedbacks' have on future initiatives. Our findings show that the d/Deaf community's vulnerability and resilience levels are influenced by insufficient levels of human capital in the d/Deaf community and emergency services, limited and uneven access to social capital (most notably information in accessible forms) and unsupportive governance structures that inhibit access to resources and inclusion in DRR processes, which erodes trust. But the greatest Inhibitors to building resilience over time are: (i) the absence of funds and clear directives to support long term sustainable change; and (ii) failures in understanding, engaging with and overcoming deeply embedded cultural divides that exist within the deaf community and the d/Deaf and hearing worlds.

Keywords: d/Deaf, vulnerability, resilience, marginalisation, inclusion, culture

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1. Introduction

Vulnerability and resilience to hazards and their associated disasters are neither uniformly distributed or evenly experienced (Dominey-Howes et al., 2014, Finch et al., 2010). Disaster experiences are influenced by socially-determined differences such as age, gender, religion, sexuality, income, ethnicity and (dis)ability (Adger, 2006, Cutter et al., 2003, Calgaro et al., 2014, Wisner et al., 2017). Consequently, the UNISDR (now called UNDRR) argue that "*the needs and concerns of all social groups …… must be necessarily integrated into the disaster reduction policies and measures because the level of vulnerability depends on these social aspects*" (Ginige et al., 2009: 24) and the Sendai Framework for Disaster Risk Reduction (2015-2030) formalises this inclusionary call (see UNISDR, 2015, pp 12-13, Guilding Principles 'd' and 'g' in particular). Looking at the experiences of women and girls, Cutter (2017: 117) observed that "what gets measured gets done, but in the case of women and children they are often the undocumented victims… reproducing the notion of the *forgotten casualties*". Extending this further, we suggest that any undocumented victim/survivor of disaster represents a '*forgotten casualty*'. This includes d/Deaf[1] people - a cultural and linguistic minority with an invisible disability who are our focus. Overlooking the '*forgotten casualty'* entrenches our blindness to the particular needs of certain social groups in the context of disaster and upheaval and the socio-economic and political contexts that generate and perpetuate states of disadvantage, marginalisation and exclusion (Gorman-Murray et al., 2017). It also stops us from recognising and capitalising on the unique capabilities and adaptive capacities that marginalised groups possess and can use to build resilience (Calgaro et al., 2020, Gartrell and Hoban, 2013, Marlowe, 2013, Wisner, 2003). Where government and emergency service resources are stretched ever thinner, grounded research that documents and engages with inclusionary challenges and solutions is critical (see Moser, 2009).

However, identifying the needs and barriers that *'forgotten casualties'* face in responding to risk along with community-generated solutions will not, in and of themselves, bring about positive change. Change requires capacity, political will, and a continuous commitment to monitor, evaluate, and adjust. From a systems perspective, documenting how chosen actions influence vulnerability and resilience levels over time and space - why actions are taken (or not) and the longer-term consequences of these actions as they feed back into the system - is essential for uncovering the true nature of the 'system' and its propensity to adapt and change (see Adger, 2006, Calgaro et al., 2014, Folke, 2006, Moser, 2009, Turner et al., 2003). It is also a crucial (yet much overlooked) step for researchers who are committed to supporting the transition to more sustainable practices (Birkmann, 2006, Kasperson et al., 2005).

1 Deaf people that subscribe to this culturally loaded identity that revolves around sign language refer to themselves as being 'Deaf' (spelt with a capital 'D'). This cultural identity is in stark difference to the one taken by 'deaf' people (spelt with a small 'd') and 'hard-of-hearing' people; both define themselves in terms of their lack of hearing ability and physiological disability and prefer to communicate using speech, listening (with the help of hearing aids) and lip-reading (Macready, S. 2009). However, the lines between the two deaf-related identities can still be blurred. Some 'deaf' people may still use sign language as their main communication tool but lack a strong cultural affinity with the Deaf culture. Given the very personal nature of identity labels, we choose to use the term "d/Deaf" to capture and acknowledge people who connect in some way to sign language and Deaf culture.

In this paper, we therefore present two distinct yet interlinked research-driven narratives from a systems perspective. First, we present the findings of a vulnerability and capacity assessment (VCA) undertaken to determine the needs and challenges of d/Deaf people living in New South Wales (NSW), Australia, that are exposed to various hazards. This assessment concludes with the presentation of community-driven resilience-building solutions. Second, we describe 'what happened next' – that is we outline the resilience-building actions taken in response to the research and reflect on their value in transforming inclusive DRR processes for d/Deaf people. The paper is set out in four parts. Section 2 provides an overview of the challenges d/Deaf people face in responding to risk. Section 3 introduces the d/Deaf Community of NSW; identifies the natural hazards they are exposed to and provides an overview of the methods used to better understand risk levels in the NSW d/Deaf Community. Section 4 unpacks the empirical findings to reveal the complex and culturally embedded factors and processes that influence d/Deaf people's ability to effectively prepare and respond to hazards and disasters and presents community driven solutions. The final section (Section 5) examines the successes and longitudinal challenges of implementing Deaf-inclusive DRR initiatives, actioned through the *Get Ready!* Project, and reflects on their long-term value in supporting more inclusionary DRR practices.

This highly reflective three-step, longitudinal process is necessary and powerful. First, identifying the specific needs and challenges that d/Deaf people face provides emergency managers, d/Deaf support organisations and community members with the knowledge needed to design and implement effective resilience building strategies. Second, the identification of community-generated solutions helps empower d/Deaf people to take greater ownership of their preparedness to risk and become active and vocal agents of change within their own community, all of which increase resilience. Third, monitoring *how* empirically based preparedness solutions play out in the real world unearths deeper insights into how vulnerability and resilience processes evolve over time and space and provides entry points for effective action in the future. Consequently, this paper advances the developing scholarship of disability inclusive disaster risk reduction (DiDRR) by bringing notions of vulnerability and marginalisation experienced by d/Deaf people into conversation with issues of culture, action and empowerment - all using a systems approach.

2. The challenges d/Deaf people face in responding effectively to risk

One of the ongoing challenges in meeting the needs of marginalised groups is access to, comprehension of, and trust in accurate information on risk and appropriate responses (Arlikatti et al., 2014, Lazrus et al., 2012, Marlowe, 2013, Shepherd and van Vuuren, 2014, Spence et al., 2011). Globally (and in Australia) governments and their emergency services are tasked with the responsibility, often cooperatively with the media, of providing timely and accurate information to 'the public' across the various phases of the disaster cycle. Having information and sufficient knowledge does not guarantee effective risk reduction or response action (see Fischhoff et al., 2000, Kasperson et al., 2003, Lazrus et al., 2012, Paton, 2007, Rippl, 2002). We, as human beings, are more complex than this but knowledge, or lack thereof, is key. If we do not have any knowledge of risk or a hazard event - which can be obtained through the provision of information and via direct experience - we have nothing to plan for or react to. But some subgroups of the

community, such as people with disabilities and culturally and linguistically diverse (CALD) populations, fail to receive the necessary information in accessible and culturally appropriate forms and distribution channels (Arlikatti et al., 2014, Calgaro et al., 2020, Lazrus et al., 2012, Marlowe, 2013, Neuhauser et al., 2013). d/Deaf people are one such group that have limited systematic, institutionalized and reliable means of receiving timely and accurate preparedness and response information (Kent, 2011, Engelman, 2012b). For example, between January to March 2020, much of southeast Australia was gripped by the most unprecedented bushfire crisis in the nation's history (Morton, 2019) and d/Deaf people struggled to gain consistent access to information during live TV emergency information broadcasts (Tatham, 2020).

Research on d/Deaf peoples' experiences with hazards and disasters reveals that *communication barriers* are one of the greatest inhibitors to preparedness and effective response for those who are culturally Deaf (Ivey et al., 2014, Stout et al., 2004, Wisner, 2003, Takayama, 2017, Engelman, 2012b, Skøt et al., 2017, Wood and Weisman, 2003, Neuhauser et al., 2013). Deaf people often have little knowledge of hazard, risk and disaster (Neuhauser et al., 2013, Wood and Weisman, 2003, McKee, 2014) and how to prepare and respond (Engelman and Deardorff, 2016, McKee, 2014, Neuhauser et al., 2013, Tannenbaum-Baruchi et al., 2014) due to:

a. Disproportionately low literacy levels – an outcome of limited or interrupted access to education that makes written preparedness directives with technical language inaccessible (Neuhauser et al., 2013, Cripps et al., 2016);
b. Limited access to information in appropriate formats (e.g. sign language, closed captions) and mediums used to deliver emergency messages during an event (e.g. TV and radio alerts, door-to-door messaging, loud-speaker alerts, social media) since they are usually audio-based (Takayama, 2017, Neuhauser et al., 2013, Ito et al., 2013, Tannenbaum-Baruchi et al., 2014); and
c. Deaf people's difficultly in communicating with emergency responders and emergency shelter staff due to language barriers and shortages of qualified sign language interpreters who are often themselves impacted by the same disaster (Engelman et al., 2013, Tannenbaum-Baruchi et al., 2014, DHHCAN, 2004).

Consequently, d/Deaf people are frequently unaware of the location of evacuation shelters (White, 2006), unsure of who to ask for help/assistance and how (White, 2006), and are more likely to return to unsafe homes and conditions, which marginalises them further from relevant emergency information, services and support and worsens their vulnerability (Takayama, 2017). They also have difficulties in obtaining information on how to access critical resources needed to recover afterwards (DHHCAN, 2004, National Council on Disability, 2005), including the provision of post-disaster mental health support with sign language interpreters (White, 2006, Takayama, 2017, Skøt et al., 2017).

There is also a distinct socio-cultural divide between d/Deaf people and those who are either hearing or those who are audiologically deaf and hard-of-hearing but do not use sign language. Language, culture and a sense of inclusion (or exclusion) are inextricably linked (Agar, 1994, Nic Craith, 2012). For Tomlinson (1999: 18), "Culture can be understood as the order of life in which

human beings construct meaning through practices of symbolic representation . . . [that is] by communicating with each other". Attributes of culture are expressed through language, enabling the sharing of interpretations and representations of a specific 'world' (Lull, 2000). With this shared world comes trust and a willingness to connect (Nic Craith, 2012, Warriner, 2007). The d/Deaf Community are united by shared language (one or multiple sign languages out of the estimated 300 sign languages used worldwide), culture, beliefs and practices that derive from a history of common experiences transmitted across generations (Schembri, 2010, World Federation of the Deaf, 2019). As a linguistic minority, they utilise sign language as the dominant language to communicate combined with the written word (Johnston, 1998, McQuigg, 2003). In this community, one's hearing ability is not a determinant of inclusion; their cultural identity, experiences and a shared way of looking and interacting with the world are. Another shared attribute of the global d/Deaf Community (no matter where they live), is a sense of alienation or marginalisation from the hearing population that rarely understands them (White, 2006). They do not see themselves as disabled or physically deficient (McQuigg, 2003). This divide which manifests in all aspects of life, *excludes* them from the everyday workings of mainstream society and increases their vulnerability to hazards and disasters (Valentine and Skelton, 2009).

There is often a stark contrast between how emergency services categorise d/Deaf, hard of hearing, and d/Deaf blind people and how these people define themselves and their abilities (Engelman et al., 2013, Ivey et al., 2014, Neuhauser et al., 2013). d/Deaf people are regularly classified as being 'vulnerable' and having 'special needs', a position that is embedded in medical and charity models of disability that view them as either victims or needy recipients of rehabilitative services (Belser, 2015, King et al., 2019, Ha, 2016, Robinson and Adam, 2003). '*Othering*' entrenches disaster paradigms and response plans that are biased towards helping the already privileged or physically abled. Consequently, disaster responses for the disabled are often included as an add-on to core plans that are frequently seen by DRR actors as a costly burden that requires specialist services and expertise (Lunga et al., 2019, Wisner, 2003, Hunt et al., 2015, King et al., 2019), including the costs of interpreters and captioning (Engelman et al., 2013, Takayama, 2017). This model sets out to *help* d/Deaf people rather than teach, train, and support them in effectively responding to risk and becoming *agents of change* in their own right (Wisner, 2003). The needs of d/Deaf, hard of hearing, and d/Deaf-blind people are given little attention in policies and regulations in DRR planning, are routinely excluded from preparedness and response training activities and efforts continue to fall short of needs (Ivey et al., 2014, White, 2006, Engelman et al., 2013, Takayama, 2017). Furthermore, top-down, rigid and bureaucratic DRR policy, planning and consultation processes hinder the participation of community-based d/Deaf representative organisations who have the connections, trust and knowledge needed to bridge this cultural divide – all of which combine to exclude and marginalise d/Deaf people (White, 2006, Engelman et al., 2013, Takayama, 2017, Tannenbaum-Baruchi et al., 2014).

Recognising the issue of exclusion in DRR practices, the Sendai Framework for Disaster Risk Reduction (2015-2030) calls for greater inclusion of persons with disability in DRR. Yet pathways to achieving disability inclusive disaster risk reduction (DiDRR) remain unclear and fragmented due to a lack of data on needs of persons with different disabilities, an ongoing disconnect between DRR

policies and practices and disability rights-based laws and a lack of robust guidelines and lived examples on *how* to include people with disabilities in disaster preparedness - how to do DiDRR (ASB and Handicap International, 2011, Calgaro et al., 2020, EU Humanitarian Aid and Civil Protection et al., 2014, Nick et al., 2009, UNISDR, 2015, Villeneuve, 2018). DRR stakeholders often have limited knowledge about how to support DiDRR and often lack the skills and capacity needed to mainstream DiDRR, measure DiDRR successes and failures and partner with those who have the skills and knowledge they lack – specifically, Disabled Peoples Organizations (DPOs) and persons with disabilities themselves (see Calgaro et al., 2020, IFRC, 2007).

3. The Deaf Community of NSW and the hazards they are exposed to, our approach and methods

From a systems perspective (Calgaro et al., 2014), reducing vulnerability to hazards and bolstering preparedness for disasters begins with identifying *who* is at risk and the nature of that risk (*to what*). But the identification of *who* is more than the listing of demographics. It involves understanding how people identify themselves, how they operate in their daily lives and interact with each other, the culture(s) they live in and identify with, what drives their choices and actions in the face of risk, and how this risk is perceived (Thomalla et al., 2015). These characteristics and behavioural tendencies are important hooks that DRR professionals can use to build effective DRR strategies that capitalise on the strengths of a population and provide support (Thomalla et al., 2015).

The exact number of d/Deaf Community members denoted by their use of Auslan (Australian Sign Language2) in Australia and NSW (Figure 1) is difficult to ascertain due to the ambiguity of the Australian Census questions relating to language. However, according to the 2016 Census of Population and Housing, 10,114 people in Australia or 0.43% of the national population and 2,693 people or 0.36% of NSW's state population use Auslan (ABS, 2016). The actual number however, is thought to be significantly higher (Willoughby and Cook, 2013). Auslan users are clustered into:

a. Those who are culturally d/Deaf with different levels of hearing ability, ranging from mild to profound hearing loss;
b. Those who are deafblind, a smaller yet distinct sub-set of the culturally d/Deaf community with very specialised needs (including communication, home assistance, education styles and transport) that differ greatly from people who are deaf, or blind or have low vision; and
c. Hearing people who choose to use sign language to communicate with culturally d/Deaf or deafblind individuals within family units, for work, and for self-interest.

Echoing the observations of White (2006), Deaf culture provides Deaf people in NSW with a safe space where they feel understood and truly 'seen':

> *Deaf people know how I feel, what my frustrations are and my feelings. Hearing people do not know or will never understand that. It doesn't matter if a hearing person has a deaf family, this person will still never fully understand 100% of*

2 In 1990, Auslan was recognised as the 'first language of the profoundly deaf' in an Australian Government's green paper. However, Australia is yet to recognise Auslan as a formal language in legislation.

what it's like to be a Deaf person (New England resident, pers. comm. 20 November 2012).

This sense of belonging that the Deaf culture provides Deaf people in NSW is highly valued. The key advantages of belonging include: the ability to effectively communicate with others; the opportunity to meet and socialise with others in Auslan; feeling accepted and equal to others; and having a support network that they trust and rely on in times of need.

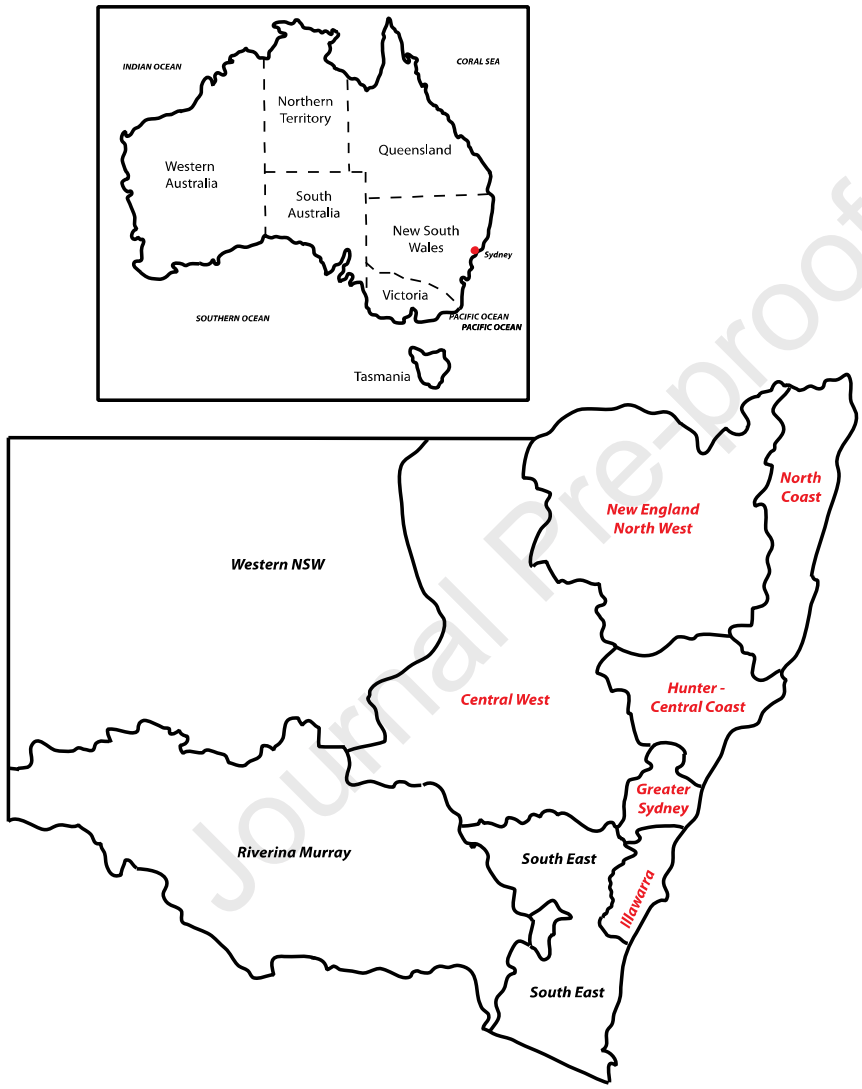

Figure 1: Location of New South Wales (NSW) and its regions in southeast Australia. Regions shown in bold red font correlate with the d/Deaf community participants in this study. Sydney is the capital of NSW

All NSW residents, including the d/Deaf are exposed to numerous natural hazards, the most common of which are hydro-meteorological (climate and weather related) such as bushfires, heatwaves, droughts, floods, storms of various types, extreme sea-level change events and pandemics (DECCW, 2010, Emergency Management Australia, 2006, Insurance Council of Australia, 2012, Seweall et al., 2016). Climate change forecasts suggest that the frequency and intensity of many of these will change (see Westra et al., 2016). Droughts followed by storms are

the most expensive in terms of insured and uninsured losses, whereas heatwaves followed by bushfires kill the most people (Coates et al., 2014). Recent research on NSW disaster declarations has revealed statistically significant 'disaster hotspots' in the northeast of NSW (Figure 2) (Sewell at al., 2016). This is important because: (i) many of the local government areas (LGAs) where these hotspots are located are amongst the most disadvantaged communities in the state (Sewell et al., 2016); and (ii) a disproportionate number of people with disability (including d/Deaf people) reside here (Zhou et al., 2018).

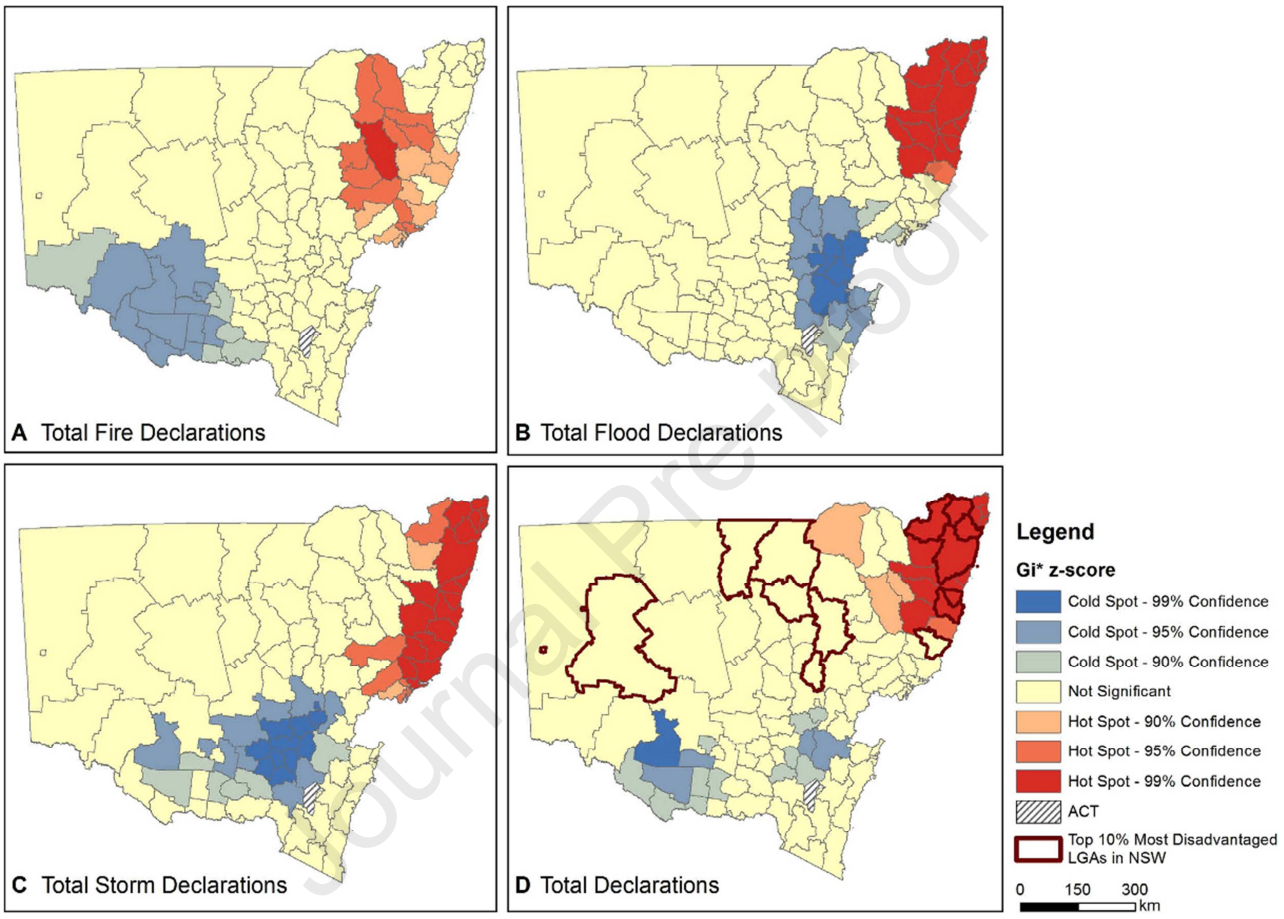

Figure 2: Disaster 'hotspots' in NSW (A = bushfires; B = floods; C = storms; D = total declarations (all types)). Bolded LGAs are those located within the top 10% of most disadvantaged LGAs in NSW. Source: Sewell *et al*., (2016)

Our research focussed on six regions (named in red bold font in Figure 1) where most d/Deaf people live spanning urban, peri-urban and rural contexts. This enabled an exploration of possible differences in both the DRR approaches and resource availability in these contexts. Three methods were included in our mixed method approach: focus group discussions (FGDs), open-ended interviews, and field observation. The research was conducted in two phases. Phase 1 comprised of FGDs and semi-structured interviews undertaken between August and December 2012. Phase 2 comprised a second round of FGDs that were undertaken in April and May 2013. This was done to present and verify key findings from Phase 1, ensure that participants were included in all phases of knowledge co-production. The sample size was 317, representing 11.8% of the identified d/Deaf population in NSW. A total of 278 participants attended the 31 FGDs undertaken. Thirty-nine

interviews were conducted, 15 of which were with Deaf Community members who had past experiences with natural hazards including bushfires, floods, hailstorms and severe storms, tropical cyclones and earthquakes.

Every effort was made to recruit a broad spectrum of people in terms of age (excluding those under 18), gender, and location. Participants were recruited via the Deaf Society of NSW (our gatekeeper organisation); personal and professional referrals; professional and social networks operating within the NSW Deaf Community; fliers and Auslan videos posted on the Deaf Society's Facebook and Internet pages; adverts in the *Deaf Herald*; and snowballing techniques. Three d/Deaf research assistants (RAs) (the co-authors – LC, NC and JA) were trained by the 'hearing' lead researchers (EC, DDH) and led the FGDs and interviews in Auslan. Guided by a process of reflexive research (Billo and Hiemstra, 2013), the Deaf research assistants played a major role in ensuring that the wording and way of undertaking the interviews and FGDs was culturally appropriate and the process was tweaked at times during data collection to adapt to feedback and ensure contextual relevance and heightened learning (Attia and Edge, 2017). The use of Deaf RAs also fostered mutual trust and understanding between the researchers and participants in ways the hearing researchers would never be able to achieve (Attia and Edge, 2017, Lincoln and Guba, 1985, White, 2006). Field observations of the FGDs and interviews and team debrief after each consultation were undertaken by the research team throughout both research phases and used to supplement and corroborate findings.

Reflections on the successes and sustainability challenges of DiDRR actions that were taken after VCA through the *Get Ready!* project were garnered from: (i) semi-structured interviews with five Disability Liaison Officers (DLOs – see Section 5.1), a representative from the Deaf Society of NSW (the project's lead organisation) and one d/Deaf Community member in the role of 'key informant'; and (ii) observations from our Deaf researcher's and co-authors (NC and LC). The interviews were undertaken between October 2019 and February 2020.

4. Factors influencing the Deaf Community's preparedness and response capabilities

Our findings reveal that d/Deaf people's ability to prepare and respond to hazards was shaped by six factors centred around access to human capital (limited knowledge of risk and low risk preparedness, limited understanding of emergency services role and a lack of Deaf awareness among emergency services personnel), social capital (limited access to information due to inappropriate communication mediums and uneven access to and reliance on social networks) and governance processes (a lack of trust in emergency services and government). However, the findings also reveal the powerful role culture plays in determining access to social capital, human capital and governance processes and influencing Deaf people's capacity to prepare and respond to risk.

4.1. Factors that heightened vulnerability

4.1.1. Limited knowledge of risk and low risk preparedness

Deaf people's knowledge of basic disaster and emergency preparedness terms (e.g., *crisis*, *emergency*, *disaster*, *hazard*) was low. Knowledge levels and perceptions of risk were also low.

Risk perceptions that Deaf people have of hazards that affect NSW (generally) and the place in which they live (specifically) also differs greatly from hazard occurrences and risk levels identified by the Department of Environment, Climate Change and Water (DECCW). Confirming observations by Paton et al. (2001), Pidgeon et al. (2003) and Thomalla and Schmuck (2004), prior experience of hazards did improve people's preparedness (i.e. more likely to have an emergency response plan in place that was followed) but this was most notable among those who had previously experienced more than one hazard. Actions taken included: moving to areas with less vegetation that could fuel bushfires; regularly clearing property of fire fuel; back-burning around the house and having hoses ready in the event of a fire; regularly checking water levels of creeks near their property; registering their address and contact details with the local emergency services; establishing a hazard action plan for the whole family; having an emergency kit ready; and regularly checking with neighbours, newspapers, radio reports (via hearing family members), weather reports, and emergency services websites to keep informed of fire and flood risk.

4.1.2. Limited access to information due to inappropriate communication mediums

Mirroring the experiences of culturally Deaf people in the USA (Ivey et al., 2014, Stout et al., 2004, Wood and Weisman, 2003, Engelman, 2012a), Japan (Takayama, 2017) and Denmark (Skøt et al., 2017), communication barriers are one of the greatest inhibitors to disaster preparedness and effective response for NSW Deaf people. Deaf participants felt greatly disadvantaged in emergencies and disasters due to their inability to access information they need to effectively plan and respond. The community's frustration with feeling disconnected and marginalised is summed up by one group of Sydney participants who felt "we always come last".

Those that had experienced previous hazards, stated that they had not received any warnings prior to those event(s) resulting in confusion, feelings of helplessness, panic for themselves and their children, and a complete state of unpreparedness. Information on how to respond effectively during the hazard event (including what to do, where to go, who to contact, and how to access basic resources like food, shelter, money, and clothes) was also difficult for them to access. In the absence of warnings and preparedness information, d/Deaf people sourced information as the hazard unfolded from multiple sources including the Internet, weather reports, radio and personally delivered updates from hearing partners, family members or hearing neighbours, warnings received from partners via SMS, and visual or physical cues. The types of sensory cues used to gage hazard threats included: checking water levels in nearby creeks to ascertain possible flood threats; observing smoke, fires, and fire trucks parked on the side of the road; experiencing the earth shaking during an earthquake; and observing the reactions of hearing people to storms and bushfires (see Calgaro et al., 2013a).

Janoske et al. (2012) and Sheppard et al. (2012) assert that effective risk communication requires five elements: (i) understanding the characteristics of different audiences, including differences in how they process risk messages; (ii) paying heed to how, when, and by whom a message is delivered and matching this with target audience preferences; (iii) keeping the message consistent and repeat it often; (iv) adapting the message and its form to changing situations and risk types; and (v) being cognoscente of the social context and secondary effects of risks. None of these

elements are present in the context of the NSW Deaf Community - this includes elements (iii) and (iv) as Deaf people struggle to access risk, preparedness and response information to start with.

Four factors hinder the effective communication of preparedness and response information:

a. *Language barriers*: Language barriers are the most common communication challenge d/Deaf people face, which affects their ability to interact with the dominant hearing/English-speaking population on a day-to-day basis. Auslan is the preferred language for culturally d/Deaf people, with English often being their second language. Not all deaf people lip-read, many are unable to speak clearly, and education and literacy levels are low in some areas (especially regional areas) due to changing models of education in Australia[3] and uneven access to quality educational support (see Malone, 2017 for more detail). This makes it difficult for d/Deaf people to communicate with hearing people. Furthermore, the language used by emergency services personnel is too advanced for many d/Deaf people. The less literate avoid asking hearing people for help because they are embarrassed. Consequently, Deaf people are often left to rely on second-hand risk-related information, response plans and directives passed down by others who can hear;
b. *Risk and response information is rarely available in accessible forms*: Information dissemination mediums (including pre-event warnings, updates and evacuation orders during the event and direct door-knocks by emergency services) are largely audio-based - radio, phone, TV broadcasts without complete captions, messages broadcast over loudspeakers in public places and direct door-knocks by hearing - and therefore inaccessible to Deaf people. Auslan interpreters are not systematically included in television broadcasts and their inclusion is often the outcome of lobbying from the Deaf Community during an event like Cyclone Yasi in 2011 and the south-east Australian bushfires of 2019/2020 (McKee, 2014; key informant, pers. comm. 29 January 2020). When Auslan is included, broadcasters tend to cut them out of the picture for close-up shots of the emergency services commissioners and/or State Premiers making the emergency announcements. In Australia, all primetime television programming is closed-captioned. But captions are often truncated, jumbled or too fast for people to read (McKee, 2014). The receipt of no information or information that is incomplete, delayed or incorrect causes Deaf people to feel both left out and panicked;
c. *Deaf people have limited options for contacting emergency services during a hazard event*: Prior to 1st July 2013, there were two telecommunication services Deaf people could use to access hazard information: (i) via Teletypewriters (TTYs) and (ii) via phone using the

3 As documented by Malone (2017), the delivery of Deaf education in Australia has changed markedly since the early 1900s. Several Deaf schools were established in the late 1800s and early 1900s. Since World War II, higher human rights concerns prompted the integration of children with disability in 'regular' education. The first step to greater integration was the introduction of oralism in 1946 into some Deaf schools, which required full delivery of education through speech with no sign language communication. The growing dominance of oralism during the 1960s and 1970s paved the way for a shift to mainstreaming Deaf children in regular schools (where additional itinerant support and classes was provided, with mixed success) in the 1980s and 1990s. These shifts facilitated declines in enrolment numbers in Deaf schools that taught in Auslan. Malone (2017) concludes that this chequered history has resulted in lower and uneven levels of education attainment within the Deaf Community.

National Relay Service (NRS)[4]. The introduction of a new national emergency contact system in 2013 saw the addition of two-way Internet relay where users ask for Triple Zero (000), SMS relay operated through the NRS, and video relay (VRS) using Skype. However, the NRS is slow, lessening its effectiveness in the rapidly changing emergency environment and has failed in the past when the Brisbane-based office flooded during the Queensland floods in 2011; and

d. There is a shortage of Auslan interpreters in some parts of NSW, making it difficult for Deaf people to access preparedness training, attend emergency drills, and limits their ability to communicate effectively with emergency services personnel and first responders as hazards and disasters unfold.

4.1.3. A lack of trust in emergency services and government

Effective risk communication also requires trust between the communicator and the audience(s) (Janoske et al., 2012) but trust in the emergency services was low due to past negative experiences. Deaf participants reported that emergency services personnel and first line responders often exhibited discomfort with having to communicate with d/Deaf people directly during emergencies and often lack the patience to use non-verbal communication mediums like pen and paper to communicate. Instead, personnel regularly chose to converse with hearing individuals, even if they were children.

Problems in accessing resources post-event also erodes Deaf people's trust in government. The process of applying for assistance and basic resources after an event was too complex for some to understand, curtailing timely resource accessibility. Post-event governmental support often came too late and fell short of meeting d/Deaf people's needs, causing frustration and mistrust in the government's ability to support them. This is detrimental to future preparedness levels. Frustration and apathy felt by d/Deaf Community members leads to a growing disconnect between communities and government support structures (in this case the emergency services and first line responders). This both deters community members from seeking help from these organisations in the future (thereby removing a needed support structure and increasing their vulnerability) and erodes the effectiveness of governance structures and processes designed to help the very people they are alienating (Calgaro et al., 2013b).

4.1.4. Socio-cultural factors that inhibit Deaf people's preparedness and inclusion

Having information provided in accessible forms and delivered by trusted sources are paramount for effective action. But disaster preparedness and response is also shaped by deeper socio-cultural factors including levels of social connectedness, knowledge and education levels, personal experiences and expectations, cultural norms and attributes, and cultural interpretations of daily life (Thomalla and Schmuck, 2004, Wisner et al., 2004). This holds true in relation to d/Deaf people's experiences in dealing with emergencies and hazards.

4 The National Relay Service enables people who have difficulty in hearing or speaking to contact support services. The call (that can be made via multiple channels and devices) In the case of Deaf people, the relay officer converts from sign language to English and vice versa.

448
449 4.1.4.1. Limited understanding of emergency services role & a lack of d/Deaf awareness
450 NSW d/Deaf people are largely unaware of the roles and responsibilities of the emergency services
451 (NSW State Emergency Services, the NSW Rural Fire Service and Fire and Rescue NSW) in relation
452 to supporting community members before, during and after a hazard. When asked who was
453 responsible for assisting them during a hazard, nearly half of the interview participants (46%)
454 named the emergency services. However, another 43% either refrained from answering or didn't
455 know. Only three per cent of participants correctly answered that they themselves had some
456 responsibility for their wellbeing and actions in emergencies. A potentially dangerous mismatch
457 therefore exists between what d/Deaf people expect emergency services to do for them in an
458 emergency and the responsibilities emergency services are mandated to provide under the *NSW*
459 *Disaster Plan* (Displan) and related national protocols (most notably the *Australian Emergency*
460 *Management Arrangements* and the *Disaster Response Plan or COMDISPLAN*). In Australia the
461 initial responsibility for hazard preparedness and response lies with individuals (Dominey-Howes
462 et al., 2016). Emergency services only step in to assist (scaling up levels) once individuals are
463 overwhelmed. This is not a Deaf-specific problem; it is mirrored in the wider population (Bohensky
464 and Leitch, 2013, Department of Premier and Cabinet, 2011, Whittaker and Handmer, 2010).
465 Being unclear of emergency service roles and responsibilities and reliance on assistance that may
466 never come leaves people underprepared and vulnerable. Conversely, most hearing people have
467 little experience with d/Deaf people and have limited understanding of Deaf culture and Deaf
468 people's needs, making it difficult for them to know how best to help and support d/Deaf people.
469 This includes emergency services personnel and first responders (Engelman et al., 2013) who may
470 exhibit discomfort with having to communicate with d/Deaf people directly.
471
472 4.1.4.2. Passivity versus activism and the role culture plays in creating this dynamic
473 d/Deaf people desire access to the same opportunities, resources, and services as hearing citizens.
474 However, some d/Deaf people believe that d/Deaf people are too passive in asking for the
475 resources they need and rely too heavily on hearing people to help and make decisions for them.
476 Instead, more active community members want to see d/Deaf people being more assertive in
477 advocating for the support and resources they need. According to one Tamworth (New England)
478 resident:

479 > *Lots of the country people are afraid to speak up [about] how they feel. Many*
480 > *times at a meeting, for example, a leader would sign and those people would just*
481 > *nod their heads, pretending to understand until at the end [when] they would ask*
482 > *what the meeting was about or what the leader was talking about. They are not*
483 > *assertive and will not put their hands up to say that they don't understand.*

484 There is a strong tendency within the d/Deaf Community to rely on hearing people to answer for
485 them or act on their behalf. The reason for this is embedded in a history of multiple layers of
486 exclusion and a multi-facetted culture that has adapted to it.
487
488 There are multiple layers of Deafness within the d/Deaf Community, which has fostered this
489 dynamic. A small core of the Community (an estimated 10%) is made up of Deaf people who grow
490 up with a strong Deaf influence, meaning they grow up in a family that includes multiple

generations of culturally Deaf people and are routinely "exposed to language, culture, 'the Deaf way' and how we function as a community…Deaf culture has its own rules" (key informant, *pers comm.* 29 January 2020). This minority are known within the Community as 'Deaf royalty'. They also benefit from being taught "how to operate in a hearing world as a Deaf person" (key informant, *pers comm.* 29 January 2020). One of our co-authors (NC) belongs to 'Deaf royalty'. The outer circles (making up the majority of the Deaf Community) are made up of: (i) hearing people who have parents and/or siblings who are Deaf and have been brought up in a bilingual context; (ii) those from hearing families whose parents have worked extremely hard to give their Deaf child a grounding in Deaf language (Auslan), speech and lipreading; (iii) those that cannot read or write due to inadequate access to schooling and education; and (iv) those Deaf Community members who have been encouraged to use speech over sign language to communicate.

Up until the 1980s, NSW Deaf schools helped to perform this role for children who did not come from 'Deaf royalty'. However, closures of Deaf schools have led to Deaf children attending mainstream schools with inadequate support, leading to layers of isolation at home (for most) and at school. "Most Deaf kids don't grow up in a society surrounded by people like them, that share their language… they don't even have friends who are Deaf to socialise with" (key informant, *pers comm.* 29 January 2020). When they become adults, they do not know how to take initiative and lead because they have always felt "like second class citizens", positioned on the outer of the wider society and have experienced multiple layers of social isolation (in their own families, at school and in their workplaces) and the anxiety and insecurity that comes with that (key informant, *pers comm.* 29 January 2020). Consequently, they are used to working in isolation, struggle to operate in the dominant hearing society and have turned to hearing people to assist them.

Another element to this dynamic is a high level of distrust that Deaf Community members have in the capabilities of other Deaf people. Deaf people are more likely to trust a hearing person because they think,

> *'if I'm missing out on information, then [other Deaf people] are missing out on information as well and the hearing person won't miss out'… They were brought up [to think] that a hearing person knows best. 'I don't trust this person because they have the same [limited] education that I had. How can I trust them?' (key informant, pers comm. 29 January 2020).*

Those from 'Deaf royalty' who understand how to operate in both cultures – the Deaf Community and the hearing world – are more likely to have the skills and confidence to lead. However, this option can also be problematic. First, 'Deaf royalty' can also be discounted as reliable leaders and discriminated against by the larger Deaf Community because "they aren't the same…That's [the majority'] upbringing, that's them not understanding that Deaf people do know a lot once they have got the language…and when they are bilingual and bicultural" (key informant, *pers comm.* 29

January 2020). Our Deaf co-authors (NC & LC) concur, adding that 'Crab Theory'[5] is very commonly practised within Deaf Communities around the world' (see also Deaf Enterprise EU, n.d.). Second, 'Deaf royalty' often get burnt out as they are few in number and struggle to carry the responsibility of continued leadership (key informant, *pers comm.* 29 January 2020).

Older Deaf people attribute this passive tendency to their limited exposure to and experience with advocating for themselves and their rights in a hearing world. Deaf Community members in New England observe that deaf people (particularly older ones) have spent many years accepting what they were given - "what more can the government do for us" - and thinking whatever they get is "better than nothing". Those that are less literate also avoid asking hearing people for help because they are embarrassed. This is a contentious cultural issue that is by no means universal. There are many Deaf people who are independent, feel empowered and are looking for opportunities that would allow them to get more involved in natural hazard preparedness activities. A Deaf resident from the Central West region in NSW sums up this willingness stating: *"I also would like to see a Deaf person work or be involved with the SES. I would if given a chance".* But culturally embedded barriers created by lifelong layers of exclusion are wide-spread and take time and support to overcome.

4.2. Factors that increased resilience levels to risk

4.2.1. Access to and reliance on social networks

One attribute that boosts Deaf people's resilience is their access to strong social networks and the emotional stability and reassurance they gain from belonging to a sub-culture that truly understands their daily struggles as outsiders in a hearing world. Deaf people often turned to trusted social networks - family, friends, neighbours (Deaf and hearing), teachers, employers, and Deaf support organisations - for logistical support and information during and after emergencies. These trusted social connections also provide emotional support and make people feel safe. Friends and family helped people access basic supplies (including food and shelter) in the immediate aftermath of hazards, providing the support needed to help stabilise the affected parties until they were able to begin the recovery process. Some people noted an improvement in relationships with neighbours and a stronger feeling of community rapport following the joint experience of hazard events. One Sydney resident observed that once distant neighbours joined together to assist each other in cleaning out gutters and filling any receptacle (including gutters) with water to help protect people's houses from fires.

However, there are significant place-based differences in the strength of community and social support networks across NSW. Some Deaf Communities (e.g. those in the Illawarra and North Coast) are very close and well-organized, creating strong support structures that emergency services can tap into. Responses from residents in Sydney, New England and the Central Coast

5 Crab Theory is based on the metaphor of what happens when you put several crabs together in a bucket. The crabs crawl over each other, trying to get out of the bucket, and in the process, none of them escape because they keep pulling each other back down. This is something that the Deaf community struggles with (Deaf Enterprise, n.d.).

were mixed, whilst Central West residents overwhelmingly felt that their cultural community was weak. One Central Coast resident reflects on these place-based differences:

> *In Berowra [Sydney suburb], we had great neighbours because we created and exchanged a list with our names, emergency contacts, phone numbers, email addresses, etc. as a way to communicate [with] each other on evacuation plans, emergency warnings, where to go and when to come back during and future emergencies. That concept was lovely…but here in Ourimbah [on the Central Coast] it is different…Here, in Ourimbah, no one bothers to check or share any updates with us.*

High levels of isolation experienced in rural areas like the Central West have left people without adequate support, prompting calls for more support to enhance connectivity:

> *Contacting people who live far in the country is very difficult. It's very sad. This is something that needs to be improved. I want to see the Deaf Society make efforts to contact and include deaf people in the country. How?...I think the Deaf Society needs to find a way to work with schools that have deaf students to share and exchange information (Central Coast resident, pers. comm. 15 November 2012).*

4.3. Community-driven solution to improve resilience and inclusivity

d/Deaf people identified numerous strategies and actions to help them anticipate risk and better respond to future natural hazards. These focus on improving access to information and building capacity are summarised in Table 1 (see Calgaro et al., 2013a for more details).

Table 1: Solutions for increasing the resilience of d/Deaf people to natural hazards

Improving access to information - general actions
• More visual hazard warning signs along roads and in public areas including those that advise the public of risk and numbers (including SMS-based services) that people can use to inform emergency services of observed hazards • Introduce a central register system administered by emergency services/local councils/Medicare where people with disabilities can register their needs and contact details to make it easier for emergency services to know how many Deaf people there are in a given area, where they are and what their specific needs are. This would enable emergency services to allocate resources where they were needed • Increase access to Auslan & deaf-blind interpreters during emergencies • Emergency services (or Deaf Liaison Officers - see below) to provide residents with updates via doorknocks during hazard events • Improve awareness of and access to GPS system that tracks weather conditions, road blocks and provides alerts on approaching natural hazards • Combine plain English text with pictures in written forms of communication to increase accessibility and understanding for Deaf people • Councils/emergency services/Centrelink to distribute regular newsletters and pamphlets on hazard risk, preparedness, and response • Deaf support organisations to disseminate natural hazard and emergency information

Improving access to information - specific telecommunication solutions
• Establish a direct SMS "000" emergency contact number that removes the NRS as the 3rd party • Receive SMS Emergency Warning Alerts from emergency services • Video Relay Service (VRS) to contact Emergency Services • Creation of more smartphone apps like *Silent Tweets* and RFS's NSW *Fires Near Me* app • Alert icon app that can locate users during emergencies • Creation of central website providing emergency information for all hazards and disasters (in simple, plain English) • Increase access to emergency information through the Internet (Auslan videos, captioned videos) • Create one central government emergency service website for people with disabilities • Wider use of social media through the Internet (Facebook, Twitter) • Provide state-based digital emergency notices through Tele-text, TV and twitter feeds
Capacity building and educational needs
• Provide Deaf Awareness Training for emergency services and the public • Run regular hazard awareness and preparedness workshops for Deaf people • Train emergency services on how to receive NRS calls from Deaf consumers • Emergency services to train and employ Deaf Liaison Officers - Deaf people that are trained in disaster preparedness who can work directly with both the Deaf Community and emergency services to improve community hazard preparedness and awareness and increase Deaf awareness in the emergency services • Improve interpreter skills (via training) for emergency situations • Provide training for deaf people (particularly seniors) on how to access information on the Internet • Deaf Society of NSW to provide 24/7 emergency support

5. What happened next – implementing grounded d/Deaf-specific solutions to increase resilience levels and foster inclusionary DRR practices

The research and community-led recommendations set out in Table 1 have inspired multiple projects and created a trajectory of work, momentum and change aimed at building the resilience of people with disabilities (including Deaf people) to risk in Australia and in the Asia-Pacific and creating more inclusive DRR processes (summarised in the supplementary material). However, here we focus on the outcomes of one of the 'big wins' for the Deaf Community of NSW - the *Get Ready!* project (2014-2016) that actioned key recommendations from our research.

The aim of the award-winning[6] *Get Ready!* project was to increase the preparedness of Deaf, Deaf-Blind and hard-of hearing community members and promote greater inclusion in DRR processes (Calgaro et al., 2020, Roberts, 2018). In line with universal design principles, the project was highly collaborative from inception to implementation and focussed on fostering inclusive community development and capacity-building (see Calgaro et al., 2020 for more details). Led by the Deaf

6 Winner of the 2016 Resilient Australia Community Award (for NSW) and the 2015 New South Wales Disability Industry Innovation Award for Community.

Society of NSW, this project was a collaborative endeavour involving: the action researchers involved in this paper (EC, DDH); the three NSW emergency services organisations that are legally mandated to assist in emergency situations (the NSW State Emergency Services (NSW SES), NSW Rural Fire Service (RFS), Fire and Rescue NSW); the NSW Office of Emergency Management; and the Australian Red Cross (ARC). Below, we detail the successes and challenges of this project and what this means in terms of building resilient d/Deaf Communities.

5.1. Get Ready! successes

Get Ready! achieved several 'big wins' in advancing d/Deaf people's preparedness to risk and increase their inclusion and collaboration in DRR practices and processes. The biggest win was the *training of nine Deaf Liaison Officers (DLOs*) who had strong community links. These nine Deaf community volunteers received basic emergency management and preparedness training in bushfires, floods, storms and house fires and leadership, community development, workshop delivery and mentoring (Roberts, 2018). The creation of DLOs is an Australian first with multiple benefits. DLOs provide a culturally appropriate and active bridge between emergency services and the Deaf community. They (Roberts, 2018): (i) deliver emergency preparedness workshops to children and d/Deaf and hard-of-hearing people in collaboration with emergency services personnel; (ii) advise emergency services on appropriate preparedness resource content and form; (iii) disseminate preparedness information to their community through established networks; and (iv) led eight Deaf Awareness Training sessions for emergency services, which provided 245 personnel with the skills and cultural awareness needed to effectively communicate and work with Deaf people. Second, the DLO initiative provides a platform for greater Deaf-led leadership in DRR through the upskilling of motivated Deaf individuals. Finally, it offers DRR actors a grounded blueprint for greater inclusion for minorities in DRR processes through cross-cultural collaboration and a shared understanding. The other tangible 'win' was the co-creation of accessible risk and preparedness information. Most, notably, the ARC's national *RediPlan* was translated into Auslan, resulting in the production of seven videos. These videos are used as the basis of community preparedness workshops delivered by DLOs.

Observations by the DLOs also reveal two critical intangible wins that have changed attitudes and beliefs. First, the risk awareness and preparedness training delivered by DLOs (a trusted community source) and greater community engagement with emergency services has delivered a breakthrough in how Deaf people perceive their own role in preparedness. A common passive mindset (highlighted in Section 4.1.4) has shifted more toward action and ownership:

> *One achievement from this was the change in perceptions. d/Deaf people realised they cannot play the 'deaf card' where they automatically assume someone will be there to help or save them. They need to understand that it is them that needs to be proactive in preparing themselves for natural disasters and hazards otherwise their [vulnerability to] risks will be high... (DLO 1, 2019, pers. comm., October).*

Second, DLOs and the *Get Ready!* activities have made Deaf people more visible to emergency services, resulting in: (i) an increased acceptance and provision of Auslan interpreters in all major

emergency announcement broadcasts; and (ii) the creation of champions within the emergency services to help advocate for sustained inclusion.

5.2. Challenges to sustaining the 'big wins'

Despite the successes of *Get Ready!*, DLO reflections of the project's outcomes three years after completion (a temporal reflection missing from many action-research projects) has revealed critical sustainability challenges that weakened momentum and the durability of its successes.

5.2.1. The project's scope was too ambitious

DLOs felt that the scope was too ambitious in terms of training quotas (including the amount of both the DLOs selected and the eight Deaf Awareness Training sessions they delivered) and the geographical spread of activity (DLO 1, 2019, *pers. comm.,* October; DLO 3, 2020, *pers. comm.* February 2020). To increase inclusivity and match demand, the original target of training four DLOs in greater Sydney was extended to nine to accommodate interest and create a larger cohort, which could support each other. Whilst conceptually sound, this stretched resources, which lessened the quality of the DLO training and left little time or resources for ongoing support. Consequently, there was no time for monitoring DLO's individual progress, including the provision of individual feedback and implementation support whilst skills were honed in the process of 'doing'. This included much-needed additional support for those DLOs that struggled with more advanced English and DRR terminology that had no equivalent signs in Auslan (DLO 3, 2020, *pers. comm.,* February). One DLO explained:

> *"We have delivered several Get Ready workshops however what happened after that? Evaluation forms were provided at the workshop but none of the DLOs had access to those feedback. We did not know what worked well and what did not. How could we improve if we do not know what the gaps are or what areas are needed to improve on? All we knew was OK, we need to provide community workshops…then what? (DLO 1, 2019, pers. comm., October)."*

5.2.2. Clear directives on how to sustain DLO activity post-project were missing

Steps on how to maintain momentum and continuity after project completion were inadequate. On completion, leadership and support from the Deaf Society largely ceased and there was little discussion between the Deaf Society and the DLOs on leadership options and strategies to enable the DLOs to move forward as a confident and active cohort. DLOs with less confidence were unsure of how best to strengthen their relationship and networks with the emergency services (being a core component of the DLO initiative) and were not given any advice on where to source additional support. As argued in Section 4.1.4, many Deaf people lack confidence in engaging meaningfully with the hearing world and DLOs felt more sustained support was needed to foster these relationships that extended beyond the project's lifetime.

5.2.3. *Team building and leadership capacity within the DLO cohort was inadequate*

Multiple layers of cultural isolation have resulted in a dearth of leadership capacity within the Deaf Community. A key aim of the DLO initiative was to upskill and empower Deaf people to become knowledgeable, culturally sensitive community leaders in DRR through the provision of training in leadership and emergency management. However, more time, resources and training were

needed to: (i) foster individual confidence in engagement and leadership; (ii) develop the DLO cohort into a strong functioning unit; and (iii) ensure its long-term success. DLOs reported that too little attention was given to creating a solid team culture driven by common and well-understood goals and processes. This resulted in some confusion about the purpose of the DLOs, a reduction in confidence for those who needed extra one-on-one feedback and mentoring to hone their skills, and competition grew between some DLOs. 'Crab Theory' tendencies (discussed in Section 4.1.4) replaced collegiality, which curtailed the cohort's chances of durability. Furthermore, many DLOs felt that they lacked the level of skill and confidence needed to mentor and pass their learnings onto new DLO candidates once the project concluded. Instead, new recruits were left to "find their local SES" on their own and start organising community-based workshops. For one DLO, this was a "missed opportunity to pass on transferrable skills to the next batch of volunteers" (DLO 1, 2019, *pers. comm.,* October). These issues caused some DLOs to become inactive.

5.2.4. Loss of momentum due to external changes

The Deaf Community need continuity and momentum. But the momentum created by *Get Ready!* has also been lost due to two coinciding events: (i) the completion of the project in 2016 meant that there were no more funds to support ongoing DLO training and engagement that the DLOs felt they needed to be effective (DLO 5, 2020, *pers. comm.,* February; DLO 6, 2020, *pers. comm.,* March); and (ii) structural changes at the Deaf Society of NSW (hereafter referred to the Deaf Society) brought about, in part, by the rollout of Australia's new National Disability Insurance Scheme (NDIS) on 01 July 2016. The NDIS funds long-term high-quality care and support for people with disabilities and gives them more choice and control over the support they receive (NSW Government, 2020). However, the rollout of the NDIS has had unintended negative consequences; it has changed the Deaf Society from an advocacy-driven Disabled Peoples' Organisation that represented the needs of the culturally Deaf Community to a hard-of-hearing service provider who has to compete for 'business' with other service providers to remain financially viable. So, the Deaf Society has no available resources (in terms of time, money or leadership) to support the DLOs, which adds to the leadership vacuum. Without a designated leader, the DLOs have struggled in keeping the momentum going. The change in the Deaf Society's role has also eroded the community's trust in the organisation; irrespective of the reasons for this change, many Deaf Community members feel abandoned by an institution that has represented them since 1913.

6. Conclusions

d/Deaf people, like those with other forms of disability, are regularly classified as being 'vulnerable' and having 'special needs', a position that is grounded in medical and charity models of disability that view them as either victims or needy recipients of rehabilitative services. Our VCA supports this narrative, *to a point*. d/Deaf people in NSW are particularly vulnerable to hazard risk; they have low levels of risk awareness and preparedness largely due to limited access to information in accessible forms, a limited understanding of emergency services roles and responsibilities, and higher levels of dependency on family and friends for assistance. This reaffirms the experiences d/Deaf people in other countries as well as those from other marginalized or minority groups, including CALD groups, racial minorities and people with

different disabilities. But the root cause of their vulnerability does not stem from their invisible disability, as is often assumed. It is rooted in a mismatch of cultures - the dominant English-speaking hearing world, institutional cultures found within the emergency services, and the d/Deaf Community - and disaster paradigms and response plans that are biased towards helping those from the dominant culture who are already privileged. In Australia and NSW, special services are 'added-onto' mainstream DRR practices to cater for those with 'special needs' without fully understanding what those needs are.

The negative consequences of overlooking Cutter's (2017) *forgotten casualties* in this context are clear: it blinds us to the specific needs of marginalized groups as well as their latent capacities to lead change. d/Deaf people's weariness and mistrust of hearing people, including emergency services personnel and government actors, is an outcome of patterns of exclusion that begin early in life and extend into adulthood. Education levels are lower due to inadequate Auslan support in schools, whilst a dependency on hearing individuals for information and assistance is learnt and reinforced as a survival mechanism that fosters passivity within the Deaf Community and mistrust in their own capabilities as leaders. A lack of Deaf awareness among emergency services personnel has left them without the knowledge and skills to support d/Deaf people, which further entrenches the cultural divide and compounds the marginalization of d/Deaf people and their vulnerability.

The findings of this longitudinal research on the NSW d/Deaf Community and their vulnerability and resilience to risk also reaffirms the importance of documenting how chosen actions and their outcomes feed back into the system over time and space and influence vulnerability and resilience levels to future risk. The *Get Ready!* project achieved several 'big wins', most notably the co-creation of accessible risk and preparedness information and the training of the DLOs. However, the project's outcomes also show that creating an award-winning model for DiDRR and inclusion based on sound research is not enough to support sustained change and transformation. Several sustainability challenges emerged, namely: an overly ambitious scope meant there was no time for monitoring an individual DLO's progress and providing more support; inadequate team building and leadership; lack of clear sustainability directives; and a loss of momentum due to external policy forces.

Both the research and implementation projects demonstrated enthusiasm for change on both sides of the cultural divide but the *Get Ready!* project failed to plan for longevity – to help DLOs set up a structure for longevity and provide advice on how to access much needed financial and logistical support. This was a critical oversight given the culturally charged context of lifelong layers of exclusion and marginalization that take time and support to overcome. The risk exists that Deaf Community members will slip back into the opaqueness of the 'forgotten casualties' and we lose sight of the fact they need to be specifically identified, counted, acknowledged and supported. To stop this from happening, the DLOs propose a revised model for implementation i.e. reducing the size of the DLO cohort, providing clear directives on how to proceed once pilot projects are completed, and concentrating initial activity in key geographical areas to ensure the establishment of a strong skill-base and collegiality before expansion. Reflective lessons from

action-research are sometimes difficult to hear but they are the key to achieving desired change; by uncovering the true nature of the 'system' they reveal more effective pathways to transformation.

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Highlights

- Deaf people are highly vulnerable to disaster risk
- Exclusionary social processes cause heightened risk exposure & reduce resilience
- Inclusive disaster risk reduction must engage with & overcome cultural barriers
- Effective engagement requires knowledge, action &, long-term monitoring & support

Declaration of interests

☒ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.