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Submission to the Child Protection Commission of Inquiry

National Disability Services (NDS) welcomes the opportunity to make this submission to the Inquiry.

NDS has taken an interest in submitting to the inquiry, as have several of our members, because we know that children with disability are over represented in the child protection system and believe that their needs and the needs of their families are not adequately met.

Broadly, the issues we address in this submission are:

- Children with disability – receiving adequate support
- Children with disability – the Child Protection System
- Parents with disability
- Aboriginal and Torres Strait Islanders and disability

Children with a disability – receiving adequate support

The Productivity Commission (2011) stated that people with disabilities and their carers/families are among the most disadvantaged groups in Australia. This is evidenced through measures of social isolation, financial status, as well as personal wellbeing. Ultimately, this disadvantage is linked to a lack of sufficient supports as two-thirds of people requiring assistance with core activities only receive informal support. As a result, parents/carers are struggling with care, and are often resigned to the fact that their last resort is to place their child with a disability into state care. Anecdotal evidence suggests that the relinquishment of care of a child is an extremely difficult and distressing decision, and is generally made after years of struggling to cope as primary carers in an environment that significantly lacks in available supports.

Example:

“Withdrawal of informal care is a last resort: These families simply couldn’t cope any longer — both lived some distance from the city — but would have, and wanted to continue their role, if only the necessary services, respite, transport, emotional and physical support had been available. They were not ‘unwilling’ to care — they were ‘physically, financially and emotionally unable to care’.”

“The only way to get help, we were told, was to relinquish our little girl to DoCS (community services). Eventually we could not cope and found ourselves in a world where authorities find it hard to distinguish loving parents from those who abuse their child. It was wrong. We are now back to lobbying for a package, and have been told we will only access one if we go into crisis or relinquish care. I used to wonder how parents could do that, but I see it's the only option.”

“The child is now, legally ‘abandoned’, and in ‘need of protection’ because of that family abandonment. This is an emotionally destroying process, with the parents having to deal with their appearance before the magistrate, the court-room processes and overwhelming sense of guilt”

“In Qld the pressure on families often results in families making the heartbreaking decision to relinquish their disabled child or young adult to the Dept. of Child Safety or DSQ. This puts further pressure on these agencies to provide support that they are not really equipped to provide.”

The process of relinquishment places great stress on parents/carers, and further demands on formal supports. In a 2005 study, 34 per cent of sole carers considered relinquishing care, and a number of carers do relinquish the care of their child with a disability because the care load is beyond family capacity and resources. They are generally offered inadequate family assistance. Cruelly, substitute care families are given a higher level of formal support.

A significant deficiency of the Queensland Disability Service Sector is its predominantly static and crisis-driven approach to support needs. This lack of certainty results in great difficulty in planning for the future for those living with disability. Consequently, carers/parents face great uncertainty with regards to care arrangements that will eventually be needed when they are no longer able to provide the care required. The cost to the system of delivering support to those who have been relinquished is significantly higher compared to the cost of delivering proactive and early intervention supports that assist in the prevention of crisis situation.

The proposed National Disability insurance Scheme will address the issue of reactive and insufficient supports. In the meantime, it is worthy of attention across both the disability and child protection systems that a more proactive approach to supporting families well before they get to the stage of relinquishment be considered, particularly to address the cruel irony of formal carers being provided with the levels of support desperately needed by families to maintain their caring role.

Children with disability – the Child Protection System

Evidence suggests that the prevalence of maltreatment of children with disability is 3.4 times higher than that for children without disability (31% as compared to 9%). It is also likely that abuse is under reported in this cohort, for a range of reasons including lack of support to make a complaint, feeling they would not be believed, not having the vocabulary or communication skills to name the harm they are experiencing, and feeling intimidation and fear commonly experienced by all children subject to abuse and neglect. Additionally, children with communication impairments, behaviour difficulties, intellectual disability and sensory disability experience higher rates of abuse, are often abused on multiple occasions and the impact of the abuse is significant.

At a societal level children with a disability often fall into categories that are strongly associated with higher incidences of abuse than those without disability. These include exposure to poverty, unemployment and under employment, inadequate housing, poor quality health care, exposure to domestic violence, and social stereotypes of vulnerability at higher levels than other populations. Children with a disability often have little or no choice or control over their lives, have multiple care providers and little or no choice over who provides that care. They rely on others for intimate personal care, live or spend significant time in environments whereby they are expected to be compliant and well behaved, rely on alternative forms of communications, are viewed negatively and as less valuable by others, and are less able to identify and report abuse which results in higher risk of and vulnerability to abuse and neglect.

As a sector we often try to provide protection to young people with disability. However, in doing so, we often withhold education about sexuality and personal safety which has left children and young people with a disability without a language to describe abuse. In Australia, there is no specific legal administration policy framework for the protection, investigation, and prosecution of exploitation, violence and abuse of people with disability and professionals have reported inadequate support to develop the skills they need to do their job well with children with disability. Children with disability, particularly Aboriginal and Torres Strait Islander children, are more often placed in inappropriate, successive out of home arrangements or stay for inappropriately long periods of time in respite care or hospital placements, which puts them in situations of risk of harm and also deprives them of an appropriate family environment.

Children and young people with a disability can at times display challenging behaviours which can result in further exposure to abuse and neglect. When children and young people have challenging behaviours, abuse and neglect can be referred to as behaviour management. These practices which are either perceived as abusive by the child and of which would be held by reasonable standard to be considered abusive or neglectful are instead framed in a behavioural context. In this instance, sometimes abuse and neglect can be unintentional on the part of the abuser. Examples of unintentional abuse and neglect include the widespread systemic failure of disability service individual plans to actively include strategies for supporting the emotional and psychological growth and sustenance of children and young people.

Ultimately, there must be collaboration by all relevant departments. The National Disability Strategy includes a focus on increasing the evidence about children with disability, exploring the interface between disability, child protection, and primary service systems, exploring evidence based models of working with families whereby the disability of the child or adult is impacting on the safety and wellbeing of that child and review the service response to children with disability in out of home care.

Additionally, risk of maltreatment is reduced in lives of children and young people with disability when:

- their dignity and humanity is understood and respected and they are treated as equal citizens
- They are valued as equal members of and actively included in their communities
- They are not isolated, either socially or physically
- They have a voice, and people who are prepared to hear and act on reports of harm
- They, and their families, have strong networks, which include people who are not paid to be there, who are there in the interests of the child and young person, and in for the long haul
- Capacity to resist maltreatment is being built at multiple levels - in individuals, within organisations, at the community level and at a broad structural/societal level
- Resources, attention and energy is put to prevention (at the whole community level, for all young people and children with disability and in responding better to those who experience harm)
- Good strong embedded safeguards, accompanied by individualised supports for children to fill valued and meaningful roles and relationships in their communities will change the life course of coming generations of people with disability
- Education and training for young people with disability, and for service providers and supporters in a range of contexts is also an essential component of abuse prevention and response, and strongly identified in the literature as a necessary component of a response

- Training for professionals working with children and young people with disability to safeguard their rights and safety, recognise harm, respond early and effectively to maltreatment, and support recovery of children and young people. It is important across both specialist and mainstream settings

Again, implementing strategies which support safe and inclusive communities and families for children with disability require a multi-system approach.

Parents with disability

Evidence indicates that a high proportion of families with a parent that has an intellectual disability will at some point attract the attention of child protection and support agencies due to allegations relating to cases of or at risk of abuse and/or neglect. Parents with intellectual disabilities represent approximately 1-2% of all parents in Australia and they are over-represented in child protection and legal proceedings. Research suggests factors contributing to the over-representation of parents with intellectual disability in child protection include discrimination, prejudice and a lack of support. Additionally, it is suggested that the evidence of child neglect brought forward before the court system is often poor and solely based on the presence of intellectual disability in a parent.

Although research in relation to parents with disability is scarce, the following studies highlight the over-representation of the population in the child protection system:

- Mothers with intellectual disability experience significantly higher parenting stress than the parents without a disability. They were also significantly more likely to experience stress associated with life experiences, having a school aged child and living in a crowded environment (Feldman, Legar & Walton-Allen, 1997)
- Mothers with intellectual disability were found to experience significantly higher levels of parenting stress than the normative sample and their stress was significantly related to having low levels of social support (Feldman, Varghese, Ramsay & Rajska, 2002)
- Self-reported maternal health of mothers with intellectual limitations was significantly worse than women's health in the Australian population (Llewellyn, McConnell & Mayes, 2003)
- Parents with intellectual disability can parent adequately if given support (Tarleton & Ward, 2007)
- A range of factors predicted quality of parenting, including following advice, quality of social networks and being accepted in a local community (Willems, de Vries, Isarin & Reinders, 2007)
- Parents with an intellectual disability identified that their greatest unmet needs were help with understanding of child development and increasing community participation (Llewellyn, McConnell & Bye, 1998)
- Parents with learning difficulties were found to be disproportionately represented in care proceedings and their children were more likely to be removed from the family home (Booth, Booth & McConnell, 2005)
- A disproportionately large number of children of parents with an intellectual disabilities were removed from the primary carer (McConnell, Llewellyn & Ferronato, 2000)
- The over representation of parents with intellectual disability in care proceedings was found to be due to enduring beliefs about parental incapacity, poorly resourced legal representatives, lack of suitable support services and the diagnostic-prognostic rationality of decision making (McConnell, Llewellyn & Ferronato, 2002)

- Only 10.2% of children of parents with learning difficulties in the court sample returned home (Booth, Booth & McConnell, 2004)

Research suggests that child neglect is identified as the most common type of maltreatment in care and protection court proceedings regarding families with a parent with an intellectual disability in Australia and internationally. Parents with disabilities often experience higher levels of social isolation, socio-economic disadvantage and unemployment putting them at a higher risk of being involved in the child protection system. The high rate of parents with intellectual disability involved in the child protection system suggests that there is a significant gap in effective services for parents with intellectual disability. Focusing support services on socio-economic disadvantage may help to reduce risks of abuse and neglect in families with a parent with an intellectual disability

In an effort to reduce the disproportionate rates of parents with a disability involved in the child protection system, the following should be considered:

- Parents are meaningfully involved in decision making
- Service accessibility is a key component to service delivery
- Learning practical skills such as healthy eating, shopping, getting children ready for school, dealing with paperwork, understanding of child development, increasing community participation and attending meetings at school were all important aspects of skills training. Behavioural based interventions and skills development should be encouraged
- The lack of data makes it difficult to assess the size of the population of parents with intellectual disabilities and the extent to which children of parents with intellectual disability are over represented in child protection services
- Research suggests that optimal services for parents with intellectual disability are family centred, provided over the long term, focused on strengths rather than deficits, home based, feature participatory rather than relational elements of practice and performance rather than knowledge based
- Strengths-based approach to support

Aboriginal and Torres Strait Islanders and disability

As stated in the emerging issues paper, although “Aboriginal and Torres Strait Islander children comprised only 6.4% of all Queensland children aged 0-17 years in 2010, they made up 29.1% of children who were the subject of a substantiated notification in 2010-2011 and 37.5% of children in out-of-home care as at 30 June 2011”. Although there is no specific data with regards to Aboriginal and Torres Strait Islander children with disability connected to the child protection system, it is reasonable to believe, given that children with disability are over represented, that Aboriginal and Torres Strait islander children with disability would be significantly over-represented.

The Productivity Commission states that Indigenous Australians have a profound or severe core activity limitation at around 2.2 times the rate of non-Indigenous Australians. It is considered that this is driven by socio-economic disadvantage and exposure to risk factors such as smoking, overweight/obesity, physical inactivity, poor nutrition and substance abuse. It is estimated that there are around 26,000 Indigenous Australians with a profound or severe core activity limitation. Indigenous children (under 15) are 3.8 times

more likely to be deaf. Statistics also reveal that over 70 per cent of Indigenous children in remote communities suffer from chronic otitis media that can cause permanent hearing loss and inhibit language and literacy development. Indigenous Australians also face significant barriers to accessing disability support services. This occurs due to social marginalisation, reluctance and mistrust when approaching government agencies, cultural attitudes towards disability and services that are not respectful of cultural differences.

Aboriginal and Torres Strait Islander people with a disability are under-represented in the support service system. Some Aboriginal people retain the fear that their children will be removed by government authorities. Furthermore that Aboriginal children remain over represented as wards of the state and that Aboriginal children with disability and Aboriginal parents with disability remain vulnerable to this fact. Additionally, there is a general sense of social exclusion, or a feeling that services are there for white people and not them. Compounding this issue is the fact that around a quarter of Indigenous Australians lives in remote or very remote areas, compared to around one per cent of non-Indigenous Australians.

A number of strategies can be used to improve accessibility of services for Indigenous people, including embedding services within local communities, employing Indigenous staff and developing the cultural competency of non-Indigenous staff. The extent to which disability services are 'in and of' the Indigenous communities they serve is a critical factor to their acceptance and success. The capacity of not-for-profit providers to be representative of the communities they serve suggest they may have an advantage over government run services in this area, particularly given the reservation that some indigenous people have about government run services. Acceptance is likely to be highest where service providers are effectively managed and staffed by the Indigenous community themselves. For this reason, block funding the provision of disability support services specifically focussed on ensuring Indigenous people with a disability can access the supports they need is a key strategy to improving service accessibility for this cohort.

The value of Indigenous staff to service providers and their clients is widely acknowledged, and there are a number of reported benefits to service providers employing Indigenous staff, some of which include:

- increased-cross cultural awareness of the organisation
- greater awareness of local indigenous issues (both cultural and political)
- greater capacity to network with Aboriginal community services and develop programs that effectively target and cater for Indigenous clients.

The State government should consider the feasibility of overcoming the barriers to service delivery for Indigenous people with a disability by:

- block funding suitable providers where services would not otherwise exist or would be inadequate
- fostering smaller community-based operations that consult and engage with local communities and local staff, with support from larger experienced service providers, in particular those with a high level of community ownership
- employing and developing Indigenous staff
- developing the cultural competency of non-Indigenous staff
- encouraging innovative, flexible and local problem solving, as well as conducting and publishing evaluations of trials in order to better understand what works and why
- developing an effective and cost-efficient balance between bringing services to remote areas, and bringing people with a disability in remote areas to services
- working with state and territory governments, indigenous advocacy groups and other community groups to develop and refine funding strategies, better understand local and systemic issues as well

as successful (and unsuccessful) approaches and diffusing this knowledge to other service providers, researchers working in this field and the broader community.

Conclusion

NDS does not propose to know all the solutions to the complex issues raised in this submission, or their interaction with other issues addressed by the Commission of Inquiry, but welcomes the opportunity to raise awareness and propose some strategies to begin to engage with these issues. Most critically, the discussion needs to be across the whole of government and communities to ensure that resources and supports are meet people's needs in the most efficient and effective way possible.

About NDS

National Disability Services is the peak industry body for non-government disability services. Its purpose is to promote quality services and life opportunities for people with disability. Its Australia-wide membership includes around 800 non-government organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.

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