Understanding safeguarding practices for children with disability when engaging with organisations

CFCA PRACTITIONER RESOURCE

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Child Family Community Australia | information exchange

Families Framework research domain: Challenges for families
Overview

This resource explores how an understanding of abuse and neglect, relating to children with disability, can assist in establishing child-safe organisations.

KEY MESSAGES

- Children with disability make up 8% of Australia’s population. Most live at home with their families and participate in specialist disability services.

- Historically, children with disability were cared for in closed environments, away from the public gaze. A shift in the understanding of how to view disability over the past 40 years has meant that Australian society is aiming to be far more inclusive.

- Children with disability, as a group, have a nearly four times higher risk of experiencing violence than their non-disabled peers. This can relate to how care is provided, the effect of impairment, as well as the sparsity of available programs to support children, their families and organisations.

- Safeguarding strategies include provision of protective behaviours information and education for children with disability, recognising the importance of listening to children’s voices, and embracing a community of practice approach.

- Australia needs to prioritise the collection of data relating to risk and abuse of children with disability in order to develop a clearer understanding of safeguarding practices. There is also a need to evaluate the relevance of services and programs that seek to protect children for children with disability.
Children, disability and Australian institutions

People with disability are defined in Australia for purposes of survey collections as any person with a limitation, restriction or impairment, which has lasted or is likely to last, for at least six months and restricts everyday activities. Self-care, mobility and communication are defined as core activities. Core activity restriction can be mild, moderate, severe or profound (Australian Bureau of Statistics, 2012).

The Australian Institute of Health and Welfare (2006) reported that children with disability comprise, on average, 8% of the total Australian population and that, of the children identified as living with disability, half had a severe or profound core activity limitation. This Australian data identified that boys were more likely than girls to have a disability, that the proportion of children with intellectual disability typically doubles at school age, and that almost all Australian children with disability aged 5-14 years attend school.

Most children with disability live at home with their families and participate in specialist disability services such as respite care as well as inclusive services such as early childhood services. Children with disability eligible for the National Disability Insurance Scheme (NDIS) can receive support to participate in specialist disability or inclusive settings, or a combination of both. The NDIS is managed by the National Disability Insurance Agency (NDIA) to provide funds to enhance access to community services, including mainstream services, for Australians living with disability. This includes children with significant and permanent or likely to be permanent disability.

Children with disability participate at varying levels in the context of institutional service provision. In terms of inclusive or segregated institutional contexts, children participate depending on their impairment and the services’ capacity to provide support. For example, mainstream schools may provide an inclusive setting where children are included in all classes or a special education unit where children with disability are separated from their peers although they may join in some activities during the school day. Closed institutional contexts (such as juvenile justice, detention centres and out-of-home care) include children with disability where services are provided away from the public gaze. Llewellyn, Wayland, and Hindmarsh (2016) noted that “segregation and exclusion in closed institutional contexts away from public scrutiny leaves children (and adults) with disability at heightened risk of violence and harm including sexual abuse” (p. 1).

Historical perspectives on disability

Historically, people with disability were considered to be dependent and in need of care or control, and were therefore excluded from society in closed institutional contexts (see Table 1 for more information on historical shifts in addressing the needs of children with disability in Australia; Thompson, Fisher, Purcal, Deeming, & Sawrikar, 2011). This belief perpetuated the idea that people with disability did not “fit” into society even when services were offered in the community such as in “special” children’s hospitals or group homes. This notion of “not fitting” negatively impacted the integration of children and adults with disability into mainstream society.

This approach has been overturned by new thinking that understands disability from a bio-psycho-social perspective. This bio-psycho-social approach explains that human functioning is the outcome of interactions between impairment, long-term illness or a chronic health condition (biology), the individual (personal factors) and the environment in which the individual lives (socio-cultural context). When difficulty with functioning is longer term, typically operationalised as six months or more, this is defined as disability. This bio-psycho-social approach underpins the International Classification of Functioning, Disability and Health (ICF) adopted by the World Health Assembly of the World Health Organization in Geneva in May 2001. The ICF is the standard classification for functioning and disability (see <www.who.int/classifications/icf/en/>). In the international standard language of the ICF, functioning and disability are understood as umbrella terms denoting the positive and negative aspects of functioning from a biological, individual and societal perspective.

This is best understood by reference to the United Nations Convention on the Rights of Persons with Disability (CRPD), signed and then ratified by Australia in 2008. The description of disability in Article 1 is that, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006). Social barriers can include limited participation in community events or services, barriers to accessing transport or obstacles to public spaces and recreational facilities, as well as attitudinal barriers such as “under expectation, under achievement and low priority in the allocation of resources” (UNICEF, 2007, p. 4).
Table 1: Historical shifts in addressing the needs of children with disability in Australia.

<table>
<thead>
<tr>
<th>Period</th>
<th>Policy</th>
<th>Outcomes</th>
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<td>Beginning of the 20th century</td>
<td>Closed residential institutional care for children with disability similar to policy and practices in the United Kingdom, Europe and North America</td>
<td>Disability was viewed through an “incurable” lens resulting in children and adults, particularly those with cognitive disability, being “put away out of sight and out of mind” in government and non-government institutions (Llewellyn et al., 2016).</td>
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<td>1970s onwards</td>
<td>The introduction of the Handicapped Child's Allowance in 1974 to support parents to care for their disabled child at home, public awareness, and policy advances brought about by the International Year of Disabled Persons (IYDP) in 1981 led to the landmark New Directions Report in 1983.</td>
<td>Changed policy approaches supported parents to care for their children at home, for example by providing respite care and schooling for disabled children, in an effort to “normalise” the lives of families with children with a disability and to decrease the institutionalisation of children.</td>
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<td>2010 onwards—the National Disability Reform Agenda</td>
<td>Key national developments include the National Disability Agreement (Council of Australian Governments [COAG], 2009); National Disability Strategy 2010–2020 (Commonwealth of Australia, 2011a); the National Carer Strategy (Commonwealth of Australia, 2011c); the National Disability Research and Development Agenda (Department of Social Services, 2011); the Productivity Commission Inquiry into National Disability Long-term Care and Support Scheme (Commonwealth of Australia 2011b); and the National Disability Insurance Scheme (Commonwealth of Australia, 2013).</td>
<td>Broadly the Disability Reform Agenda is underpinned by Australia’s ratification of CRPD and a commitment to human rights, and the social and economic participation of people with disability including children with disability (Commonwealth of Australia, 2011a). This objective to ensure the participation of people with disability was supported by multi-level policy responses focusing on the inclusion of individuals and strategies relevant to safeguarding the needs of all people with disability including children.</td>
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Abuse and neglect of children with disability

In 2011, the World Health Organization commissioned a systematic review and meta-analysis on violence against children with disability, including physical violence, sexual violence, emotional abuse and neglect. The review was to understand whether children with disability were more likely to experience abuse and neglect, and if so, which children, under what conditions and to what extent were most at risk of maltreatment. The review found that children with disability are at significantly greater risk of violence than children without disability (Jones et al., 2012). Children with disability, as a group, were found to have nearly four times higher risk of violence than their non-disabled peers. In terms of specific violence, children with disability were:

- at more than three times higher risk of physical violence;
- at nearly three times higher risk for sexual violence; and,
- over four times higher risk for emotional abuse and neglect.

Eleven studies met the rigorous criteria for inclusion in this meta-analysis; none were Australian. This suggests that there has been much less attention than needed to this societal problem of violence against children with disability.

Llewellyn et al. (2016) noted from the international literature, individual child, family and environmental factors contribute to the level of risk of violence. Children with mental/ intellectual disability (Jones et al., 2012; Maclean et al., 2017) and girls are at higher risk (Llewellyn et al., 2016). Grey literature in Australia suggests that children with cognitive and communication impairments, and children requiring behaviour modification/management are at highest risk (Llewellyn et al., 2016). The evidence on association of risk with child age is not conclusive. Research on what family and environmental factors contribute to higher risk of violence for children with disability is sorely lacking, and this is of major concern for policy and practice in Australia. Various authors writing in the grey literature have postulated the following risk factors:

1. Risk was reported as a risk ratio.
- segregated settings;
- children with disability being alone with an adult;
- closed and locked settings;
- organisational culture and attitudes such as those supporting a culture of closed communication; and
- poor leadership and organisational governance.

However, empirical research is needed to thoroughly investigate these factors (Llewellyn et al. 2016).

### Type of disability and risk of abuse and neglect

A recent Australian study reported on the risk of maltreatment, which included sexual abuse, physical abuse and neglect, for children with various disabilities (Maclean et al., 2017). The dataset included all children born in Western Australia between 1990 and 2010 (over 500,000 children). Children with disability were identified using population-based registers: Western Australia Register of Developmental Anomalies (WARDA), Intellectual Disability Exploring Answers (iDEAS), Mental Health Information System (MHIS), and Hospital Morbidity Data System (HMDS). Disability types included:

- intellectual disability;
- Down syndrome;
- cerebral palsy/birth defects;
- autism;
- conduct disorder; and
- mental and behavioural.

Child protection records were used to examine history of maltreatment allegations and substantiation. Data from birth registers, the disability registers and child protection records were linked. Analyses were conducted to account for child gender, aboriginality, gestation and birth weight, maternal and paternal age, mental health or substance admission, marital status, and neighbourhood level socio-economic status. When these characteristics were taken into account, children with disability had a nearly two-fold increased risk of a maltreatment allegation compared to non-disabled children. The authors reported:

- Children with intellectual disabilities had more than double the risk of a maltreatment allegation.
- The next highest risk was for children with conduct disorder, followed by those with mental and behavioural disorders.
- Maltreatment allegations were significantly lower compared to children without disability for children with Down syndrome and autism.
- There was no difference in risk of maltreatment allegations for children with cerebral palsy/birth defects compared to non-disabled children.

These findings from Western Australian linked data mirror the results of the meta-analysis by Jones and colleagues (2012). However, Jones and colleagues (2012) were only able to report risk for children with mental/intellectual disability. For other types of disability the risk estimates could not be calculated, as there were insufficient numbers. When compared to children without disability, children with mental/intellectual disability were at:

- over four times greater risk of experiencing any type of violence,
- over four times greater risk of emotional abuse;
- over four times greater risk of sexual violence; and
- three times greater risk of physical violence.
What do we know about safeguarding strategies?

Children with disability spend a great deal of time in a range of institutional settings. Some contexts, where children with disability receive support, such as respite care, school transport and support classes for children with disability, are not yet “normalised”. This means that the only children in these settings are those with disability and this may exacerbate their vulnerability. As noted by Robinson (2016, p. 72), children and young people with intellectual disability, for example, “have very different living patterns to their peers without disability” due to, among other factors, many living in or experiencing daily closed institutions away from the oversight of the broader community.

Many children with disability receive frequent intimate and personal care from one or more adults that they are not related to or do not know. There may be little oversight of these adults by others. There is a concern that this situation where adults are unknown to children—and to each other—will increase with the expanding casualisation of the workforce in the disability sector alongside the NDIS market reforms. Policies and procedures that provide adequate safeguarding to reflect this increased engagement between children and unknown adults are required in the rollout of the NDIS.

Internationally, strategies to prevent abuse and neglect of children are typically classified into four categories: strategies for the child; for the family/carer; for staff/managers; and for organisations (Llewellyn et al., 2016). Safeguarding strategies include protective behaviours information and education for children with disability, recognising children’s voices, and embracing a community of practice approach.

How can child-safe organisations for children with disability be achieved?

Protective behaviours information and education for children with disability

Children and young people with disability, like all children and young people, have the right to receive evidence-based education about what is and what is not safe touching and to be learning and practicing protective behaviours. Literature in this area reinforces that adult carers need to be taught and supported to recognise signs and changes in child behaviours that are associated with abuse. For example, injuries to private areas, children showing excessive fear when being cared for or differences in their behaviour when left with certain people (Government of South Australia, 2013). A prevention framework is urgently needed that listens to and respects the voices of children with disability on staying safe (Robinson & McGovern, 2014). Regrettably children with disability are usually “left out” of prevention programs on the assumption that these programs are not relevant and that they will not understand the content or learn what to do, or on the “naive” assumption that it is unlikely that children with disability will be abused.

Furthermore, children with disability have little opportunity for the incidental learning about staying safe that other children and young people have—in informally, in the playground and through sharing their own experiences. When organisations regard children with disability through one lens only—the “disabled” lens—children with disability are typically seen as less able, less in need of care and protection, and their rights to education about protective behaviours and being protected in child-safe organisations are neglected. Children with disability are children first and their needs for protection are paramount as a human right, especially because they are more vulnerable and more likely to experience abuse and neglect than their non-disabled peers. It is the responsibility of educators and those delivering inclusive and specialist services for children with disability to recognise the rights of these children and young people, to become informed about their heightened vulnerability to maltreatment, and to seek out—and implement—suitably adapted, evidence-based, age-appropriate educational materials.
Recognising the importance of listening to children’s voices

In order to keep children safe, Moore (2017) noted that the inclusion of children’s voices in the development of child-safe organisations is required. Robinson (2012) has begun the process of working with children and young people with disability to investigate their perspectives on what makes them feel safe, and this work is ongoing (Robinson, 2016). This approach respects the agency of children and young people with disability in matters affecting their lives as required by the United Nations Convention on the Rights of Persons with Disabilities.

Embracing a community of practice approach

Specialist disability organisations would benefit from adopting the community of practice strategy now well established in other areas including the care and protection sector. Communities of practice are action-oriented, providing the opportunity for service providers across sectors and peak bodies to share knowledge and experience and work towards improving practices “on the ground”. A move away from “isolated” specialist disability services for children to collaborative knowledge-sharing and learning to develop and maintain child-safe organisations that are inclusive of children with disability is sorely needed.

Addressing the need for change at an institutional level

It is not enough, however, to listen to and include the perspectives of children and young people with disability. For an effective practice-based approach, a whole of organisation strategy is required (Llewellyn et al., 2016), meaning that all staff in institutional settings and all workers associated with the institution need to be involved in policy, implementation and monitoring related to child-safe organisations. Leaders of organisations need to acknowledge the inherent dignity of children with disability and respect their rights (United Nations, 2006).

For all institutional contexts to be safe for children with disability requires:

- organisational leadership;
- attention to implementing, monitoring and evaluating recruitment strategies and outcomes;
- staff development policy and reporting procedures;
- initial and ongoing training of staff, and
- most critically, processes in place that challenge the culture of closed communication that has historically surrounded the notification of abuse of children with disability (Robinson, 2012).

Inclusion of the specific needs of children with disability in policy, training and practices, particularly in the education and children’s sectors, must focus on the over-representation of these children and young people in closed contexts where there is solid evidence that the risk of abuse and neglect is exacerbated (Llewellyn et al., 2016). Furthermore, effective governance and monitoring mechanisms are needed to ensure best practice, standards compliance and accessible complaint processes to ensure the rights to protection for children and young people with disability are realised.

Scope for evaluation of programs

The NDIS Quality and Safeguarding Framework (Department of Social Services, 2016) addresses issues associated with the provision of support and services in institutional settings. The framework proposes a complaints mechanism available to participants of the scheme; however, there is little specific attention to the particular issues associated with the risk of abuse and the needs of children with disability. There is an urgent need in Australia for evidence-based strategies to reduce the greatly increased risk of abuse and neglect now documented for children with disability and, at the same time, to increase our knowledge about the socio-economic, geographic and cultural demographics that may exacerbate risk for particular children with disability. The National Framework for Protecting Australia’s Children (Commonwealth of Australia, 2009) suggests differentiated approaches to address child abuse and neglect. This requires cost-efficiency and effectiveness studies to determine which approaches work for all children with appropriate attention to effective approaches for children with disability. Without evaluation studies, the capacity for the children’s sector and the disability sector to provide evidence-based prevention programs is severely inhibited.
The need for national prevalence data

Currently there are no national figures on the prevalence of abuse and neglect of children with disability and its related impact on the child and more broadly, their family. The Western Australian data presented previously identifies the risk of allegations of maltreatment; however, national data on risk of allegations of maltreatment are not yet available. The abuse and neglect of children with disability are not consistently recorded across the Australian states and territories. With no foundational national administrative data on maltreatment of children with disability there is little opportunity or incentive to develop evidence-based approaches to protecting these children from harm. Furthermore, a lack of national data means that it is not possible to monitor the success or otherwise of any prevention or intervention strategies put in place or to evaluate policy initiatives.

Policy implications

Given the significant policy and procedural changes for children and young people with disability who receive support from the NDIS, a critical examination of the adequacy of the NDIS Quality and Safeguarding Framework (Department of Social Services, 2016) is required to ensure all supports will be offered in child-safe organisations. The inclusion of child-safe strategies, identified from a policy and implementation perspective, is required. The Office of the Children’s Guardian (2017) has developed Principles for Child Safe Organisations, with four principles exploring ways that organisations can keep children safe through participation and inclusion. These strategies aim to speak to the needs of all children, with awareness of vulnerabilities that might affect their capacity to be safe. In addition, the Royal Commission into Institutional Responses to Child Sexual Abuse report Creating Child Safe Institutions (2016) provides a checklist relevant to the core work of organisations working with children. One standard, “Equity is promoted and diversity respected”, specifically identifies the ways in which organisations are required to anticipate and respond to the needs of children with additional vulnerabilities, including children with disability. The other nine standards, while not naming disability specifically, have been developed in a way that are relevant to all children, reinforcing that children with disability are children first. Identifying standards for organisations to adhere to in the delivery of services is paramount to the development of child-safe environments.

In conclusion, historical shifts in thinking about people with disability, including children, and inclusion have changed the way in which the safety and wellbeing of children with disability are considered. The current frameworks that seek to protect Australia’s children fail to identify specific ways in which child-safe organisations can incorporate the needs of children with disability. However, the work of the Royal Commission is leading change in this area by acknowledging that the increased risk of maltreatment for these children requires an appropriate and effective response.
About the authors

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Dr Gabrielle Hindmarsh is currently a Senior Research Officer at the Centre for Disability Research and Policy, The University of Sydney. Both as a clinical psychologist and a researcher she has experience in the examination of the outcomes and wellbeing of children who experience disadvantage. More specifically, children who are born with low birthweight, with disabilities, or have parents with disabilities.

Further reading

- Enabling and protecting: Proactive approaches to addressing the abuse and neglect of children and young people with disability <www.cyda.org.au/enabling-and-protecting>

References


Robinson, S. (2016). Feeling safe, being safe: What is important to children and young people with disability and high support needs about safety in institutional settings? Sydney: Royal Commission into Institutional Responses to Child Sexual Abuse.


