

December 2016

## Response to the JACS Information Sharing in the Context of Family Violence

Advocacy for Inclusion provides independent individual, self and systemic advocacy for people with disabilities.

Advocacy for Inclusion is a Disabled Peoples Organisation which means our board, members and staff are a majority of people with disabilities. We represent Canberra's most marginalised and isolated people with disabilities, those with cognitive disabilities and/or significant communication barriers.

We act with and on behalf of individuals in a supportive manner, or assist individuals to act on their own behalf, to obtain a fair and just outcome for the individual concerned. Advocacy for Inclusion works within a human rights framework and acknowledges the *United Nations Convention on the Rights of Persons with Disabilities*, and is signed onto the *ACT Human Rights Act*.

Advocacy for Inclusion hopes this submission will result in more accessible and equitable protections for people with disabilities, and bring us closer to Article 22 the right to privacy, and Article 19 the right to decide where and with whom to live, of the *United Nations Convention on the Rights of Persons with Disabilities*.

## Privacy and Self-Determination

Personal information privacy is fundamental to an individual's ability to enjoy their self-determination. People with disabilities, particularly with cognitive impairment<sup>1</sup>, must be in the best position to make their own decisions regarding the information that they share, how and with whom and to what extent necessary for other agencies to perform their role or function. In the ACT, the right to privacy is protected under the *Human Rights Act 2004*, the *Information Privacy Act 2014* and the *Privacy Act 1988 (Cth)*, yet for people with exposure to multi services and supports the right to privacy is often compromised when a decision to share information is not provided to the individual and information is shared without their consent.

People with disabilities, including those with diverse decision-making abilities, are entitled to the same privacy rights as anyone else, including collection of their personal information by lawful means, the right to access and collect personal information held by agencies, restrictions on disclosure of personal information

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<sup>1</sup> The term **cognitive impairment** is a broad term that refers to all people who have intellectual disability, psychosocial disability, traumatic brain injury, autism spectrum disorder, etc. The term refers to people for whom the ability to perceive and process information is impaired in some way, and who may require support to understand and remember information, and to communicate their wishes/intentions.

without consent unless lawfully authorised, and the right to hold organisations accountable when privacy and consent is breached in a domestic violence context.<sup>2</sup>

The *Privacy Act 1988 (Cth)*, alongside the *ACT Human Rights Act 2004* and the *ACT Information Privacy Act 2014*, underpins the open data agenda and assists in building public trust in data-sharing activities between government bodies. Advocacy for Inclusion is concerned about the privacy of information shared when collected, stored, used, disclosed or handled about a person with disability, particularly a person with cognitive impairment.

Current information sharing practices between individuals, services and agencies, in order to protect actual and prospective victims of domestic violence, has shown that the lack of training, confidence and capacity in the frontline services area is under-utilised and under resourced. Advocacy for Inclusion's frontline advocacy work regularly sees information sharing practices across a range of violence, specialist disability, and health services where people are not consulted nor given information as to how their information and private details are being shared among others.

With numerous agencies and services involved, without the knowledge or consent of the individual with disability, transparency and involvement in their own process is no longer in the control of the individual. For example, the lack of involvement provided to parents with disabilities when their children are removed from their care, particularly in a domestic violence situation, is widespread when considering information sharing between courts, Child Protection Services and other agencies.

Organisations involved in responding to domestic violence share information necessary to access and manage risk to a victim's safety and to reduce further behaviour. Yet, Advocacy for Inclusion remains concerned that information sharing and data collection between agencies and service providers regarding people with disabilities, particularly women with disabilities, is compromised when the individual has not provided adequate consent, nor had appropriately explained to them their right to privacy, in an accessible way, despite the legal obligations to do so under various Acts.

The released Gap Analysis report states that only 9% of services provided were 'well equipped' to deal with women with disabilities; the lowest score recorded across the range of issues listed in the survey.<sup>3</sup> In Australia, 18.3% of people reported having disability in 2015.<sup>4</sup> <sup>5</sup> With women with disabilities potentially being a large majority of the consumer base in the ACT<sup>6</sup>, problems of definition emerge with much of the limited data that is available through the information sharing method unable to distinguish what is considered to be 'family abuse'.<sup>7</sup> People with disabilities living in congregate living arrangements, residential shared accommodation or living in a 'kinship' arrangement are not covered by the new 'Safer Families' package to be included in the data collection. For these individuals, data collection is non-existent when finding out who is doing what to whom and their lack of privacy becomes further eroded because the safeguards in place for "family violence" victims will not be applied to them.

It is vital to alert the community about the risks of data sharing and to address concerns surrounding perceived values, risks and attitudes to privacy, particularly for people with disabilities in congregate living arrangements or shared accommodation where privacy is limited to the individual alone. The appropriate

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<sup>2</sup> NSW Information and Privacy Commission (2004), Guide: Privacy and People with Decision Making Disabilities

<sup>3</sup> *Ibid*

<sup>4</sup> WWDACT (2012) *Strong Women, Great City: A snapshot of findings from a survey of ACT women with disabilities*, Canberra <http://www.wchm.org.au/wp-content/uploads/2015/02/Strong-Women-Great-City-A-snapshot-of-findings-from-a-survey-of-ACTs-women-with-disabilities.pdf>

<sup>5</sup> Australian Bureau of Statistics (2016) *Disability, Ageing and Carers Australia: Summary of finding 2015*, Cat no: 4430.02015, Commonwealth of Australia, Canberra

<sup>6</sup> ACT Disability and Community Services Commissioner. (2014). *Developing an ACT crisis response to women with disabilities who experience domestic violence and/or sexual assault*.

<http://www.hrc.act.gov.au/res/Final%20Report%20%20Crisis%20Services.pdf>

<sup>7</sup> NSW Information and Privacy Commission (2004), Guide: Privacy and People with Decision Making Disabilities, p.50

balance between the right to privacy and the right to safety is to ensure people with disabilities are valued as owners of their own information and the right to share or withhold it.

**Recommendation 1: The ACT Government must ensure that any information sharing between agencies and organisations in the family violence or child protection systems recognises the extreme lack of privacy generally afforded to people with disabilities and ensures strong mechanisms to specifically protect the information of people with disabilities including through the development of appropriate format consent processes.**

### **‘Family Violence’ vs Domestic Violence in the ACT**

Following the announcement of the ACT Government 2016-17 ‘Safer Families’ Package, the new legislation does not include the range of settings in which people with disabilities live. The lack of definition which captures the range of relationships and various dimensions and experiences of violence experienced by people with disabilities living in group or congregate living arrangements is not included under the wide definition of ‘family violence’. Relationships, consensual or not, are not recognised if the person with disability is experiencing violence in a ‘home setting’ by support workers, co-residents with disabilities, or kinship carers.

In Commonwealth legislation, there is no classification or consensus as to what constitutes violence against women. The definitions used vary in the context of ‘domestic’, ‘spousal’, ‘intimate partner’ or ‘family violence’ which frequently excludes the violence that people, particularly women with disabilities experience in the many settings in which they live.<sup>8 9</sup> The ACT *Glanfield Inquiry* noted the general community often refers to *domestic violence* as intimate partner violence and uses the term *family violence* as the broader term encompassing violence against a variety of family members including intimate partners.<sup>10</sup> Yet, for people with disabilities this is totally inappropriate and denies the violence experienced in their own homes as domestic violence.

The Australian Law Reform Commission report *A National Legal Framework* recommended that all jurisdictions, including the ACT, provide a definition of family violence that is violence of threatening behaviour, or any form of behaviour that coerces or controls a family member.<sup>11</sup> It should be recognised that people with disabilities living in congregate living or kinship arrangements do not fall into the definition of family violence, nor do they all live in a family-living context – yet they experience violence as legally described. Their privacy or consent is further not acknowledged or present when their information is shared between agencies, both government and non-government, and this places them at higher risk of privacy breaches.

### **The severe lack of privacy and consent to collect and share information**

The Commonwealth and ACT privacy laws are currently based on the premise that individuals have a right to privacy;<sup>12</sup> however, Advocacy for Inclusion remains concerned about the exceptions within the current legal framework that effectively allow for the disclosure of personal information in circumstances where there is an overriding interest and the capacity to share information in the context of domestic violence. People with disabilities are already deprived of privacy on a daily basis, and are often not alerted when their information is shared as they have high exposure to multiple services.

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<sup>8</sup> Commonwealth of Australia, 2010

<sup>9</sup> WWDA, *Preventing Violence Against Women and Girls*, 2015

<sup>10</sup> *Glanfield Inquiry Report*, f.4, p. 22: [http://www.cmd.act.gov.au/\\_\\_data/assets/pdf\\_file/0010/864712/Glanfield-Inquiry-report.pdf](http://www.cmd.act.gov.au/__data/assets/pdf_file/0010/864712/Glanfield-Inquiry-report.pdf)

<sup>11</sup> Australian Law Reform Commission (2010) *Family Violence - A National Legal Response*. ALRC Report 114. *The Intersections of Child Protection and Family Laws*. <https://www.alrc.gov.au/publications/family-violence-national-legal-response-alrc-report-114>. P. 36.

<sup>12</sup> ACT *Information Sharing Act 2014*; ACT *Human Rights Act 2004*; *Privacy Act 1988 (Cth)*

The tick of a consent box is irrelevant in declaring absolute consent when an individual is considered not to have an 'understanding' capacity to allow sharing. It is common for consent to be considered unnecessary when it is assumed that an individual with a cognitive impairment will not understand why their information is being shared among agencies; therefore it is a matter of 'pressing on' and not complicating or slowing down the process. Bureaucratic expedience becomes directly responsible for the erosion of privacy for people with disabilities.

It needs to be explicitly understood that an individual's capacity may depend on the appropriate supports provided to enable them to exercise their capacity. Many people with cognitive disability are able to make decisions if information is communicated to them in a way that is appropriate to their individual abilities and methods of understanding. It is critical that information is provided in an Easy English format to ensure the greatest level of accessibility for people with cognitive impairments, alongside an assumption of decision making support, so that all people are able to consent directly to their information being shared.

It relies on the person's ability to understand elements of the way their personal information is being collected and disclosed and that they have the right to access and correct their personal information. There remains insufficient legal provision for information sharing in family violence cases and the balance between the right to safety and the right to privacy must be recalibrated in order to better safeguard victims of domestic violence and to improve service delivery through information sharing.<sup>13</sup>

We acknowledge this complexity between current privacy laws and legal barriers, but the right to privacy becomes more fraught with the addition of the National Disability Insurance Scheme (NDIS) to the multiplicity of services people with disabilities are exposed to. This has created a further avenue for information to be shared between the individual and service providers. We are concerned that when adding domestic violence to the equation of 'rights' between privacy and safety, there is risk of further reducing the autonomy of the individual and their decision-making rights. Few disability specific environments – residential care, institutions, group houses, cluster housing, congregate care, and psychiatric institutions - are recognised under domestic violence laws and information sharing protocols.

For people with disabilities, the ability to consent or withhold consent to what occurs with their personal information is fundamental to privacy. It increases an individual's control over whether and what personal information is known to others including government agencies, private organisations, guardians, family and professionals. It is essential that a person with disability be afforded self-determination and the right to make decisions about matters affecting them directly.

In the *Information Sharing Act 2014*, personal information explicitly does not include personal health information regarding the individual<sup>14</sup> – this includes information about their disability. Consent is only genuine if the person providing the consent has the capacity to give or withhold consent. Current measures of obtaining consent from government and non-government agencies do not have the means to obtain voluntary, informed, specific and current consent when a form is not provided in Easy English format, or reliance is placed upon guardians and/or family members to provide consent on someone's behalf. Fundamentally, current information sharing and privacy legislation needs to be interpreted on a daily basis based on entity, not a one-size-fits-all generic measure.

**Recommendation 2: Robust firewalls regarding information sharing and privacy of people with disabilities, particularly where consent is concerned, must be in place for all information held.**

**Recommendation 3: That the ACT government develop robust guidelines for agencies and organisations working in family violence services to recognise the culture and risks associated with sharing of information of people with disabilities living in congregate or 'kinship' arrangements to ensure further erosion of their privacy is explicitly prevented.**

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<sup>13</sup> *Glanfield Report, 2016*

<sup>14</sup> *Information Sharing Act 2014, s.7(8b)*

## Conclusion

Information sharing and privacy needs to be supported through strong policy and procedures and a clear mandate to both government and community providers that they respond to and support clients with disabilities, who have been experiencing domestic violence, with specialist awareness of the need for extra privacy protections.<sup>15</sup>

The new ACT Government 2016-17 'Safer Families' Package fails to recognise that people with disabilities do not all live in 'family-like' arrangements. Relationships, consensual or not, are not recognised if the person with disability is experiencing violence in their home by support workers, co-residents with disabilities, or kinship carers and this impacts on how information sharing should consider the privacy of individuals in these settings.

It is imperative that people with disabilities are considered when their privacy is shared among government agencies, service providers and even family members or guardians when the channels are further opened to allow "fluidity" to information sharing. The privacy of people with disabilities is already heavily eroded and the issue of lack of consent and disregard for individual privacy is at high risk of becoming further diminished with increased information sharing protocols.

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<sup>15</sup> Gap Analysis Report (2016), p.40