

advocacy for  
**inclusion**

Submission to  
ACT Budget Consultation 2013 - 14

Advocacy for Inclusion  
February 2013

## **About Advocacy for Inclusion**

Advocacy for Inclusion acknowledges the Ngunnawal people as the traditional owners of the land on which we work.

Advocacy for Inclusion provides individual, self and systemic advocacy services for people with disabilities. We provide information, education, and representation to effectively advocate for positive and inclusive outcomes for people with disabilities.

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 the *ACT Human Rights Act*.

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## 1. Introduction: Choice and control – the future for people with disabilities

Choice and control is the new consistent theme of policy discourse for people with disabilities in Australia and internationally. It is widely recognised as the way of the future and is emerging as the central component of social policy concerning people with disabilities. This includes the fast approaching National Disability Insurance Scheme (NDIS), which intends to allow people with disabilities “much greater power and choice in a new system, with the objective of giving people greater flexibility and control over their lives — with the ultimate goal being greater wellbeing.”<sup>1</sup>

The ACT has a long way to go to support choice and control for people with disabilities. The NDIS will provide a funding framework to facilitate greater choice and control; however, it will not result in choice and control on its own due to structures and attitudes among the ACT community that prevent it including:

- Long lasting community attitudes that arise from the history of oppression and segregation;
- Continuing practices of segregation and exclusion;
- Disbelief among the community that people with disabilities can be self-determined;
- Lack of Supported Decision Making mechanisms and the continuing use of guardianship practices;
- Lack of experience and support for people with disabilities to have choice and control;
- Lack of advocacy for people with disabilities;
- Structures and practices that deny the human rights of people with disabilities and their inclusion in the community;
- Lack of access to justice for people with disabilities.

These barriers continue to make choice and control for many people with disabilities unattainable in the ACT. The ACT must address these barriers in order to advance, rather than resist, the progressive human rights based policy directions of the NDIS and other key frameworks.

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<sup>1</sup> Productivity Commission. (2011). Disability Care and Support. Report no. 54, Canberra. p. 343

## 2. Summary of Recommendations

1. Improving the inclusion of people with disabilities must be the driving force behind all ACT public policy, including by targeting community attitudes and structures that exclude or segregate people with disabilities.
2. Allocate and provide the resources necessary for residents to move to individualised community based housing and support options which will support their inclusion and participation in the general community.<sup>2</sup>
3. The ACT to actively phase out systems and facilities that segregate people with disabilities from the community and increase supports and resources to support people with disabilities to live, work and be educated in the community. This should be done by halting further funding to segregated systems and instead divert it to supports and resources for inclusion.

### Self Determination

4. Any funding for training and development in the disability sector must be matched by funding for Self-advocacy and Supporting Self-advocacy training, especially in the lead up to and for the first decade of the NDIS.

### Self Determination and Mental Health

5. The ACT to allocate 10% of the Mental Health budget growth funding, over the forward estimates, to targeted disability self-determination services as part of the response to reducing the high rates of mental illness among people with disabilities.

### Supported Decision Making

6. The ACT to fund the development of a Supported Decision Making trial in the ACT as part of the suite of activities to support choice and control of people with disabilities in the lead up to the launch of the NDIS, with the view to expand Supported Decision Making as an alternative to Guardianship.
7. Review the *Guardianship and Management of Property Act 1991 (ACT)* with a view to compliance with the ACT's obligations under the CRPD and in line with the recommendations of Advocacy for Inclusion's report, *Supported Decision Making, legal capacity and guardianship*.<sup>3</sup>
8. Undertake an audit of all ACT legislation to investigate the right of all people in all situations to equal recognition before the law; the audit should investigate the presumption of legal capacity for all people, and extend to those circumstances where support may be required for a person to exercise their legal capacity.<sup>4</sup>

### National Disability Insurance Scheme Launch Site

#### Preparing for Self-directed Funding

9. The ACT must fund independent non-service organisations to provide training, mentoring and support for people with disabilities to prepare for the NDIS including:
  - the basics of money and budgeting;

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<sup>2</sup> Shut In. (no date). Shut In: Campaign to close institutions. <http://www.shutin.org.au/>

<sup>3</sup> Advocacy for Inclusion. (2012). *Supported Decision Making, legal capacity and guardianship*.

[http://www.advocacyforinclusion.org/publications/supported\\_decision\\_making\\_legal\\_capacity\\_and\\_guardianship2012final.pdf](http://www.advocacyforinclusion.org/publications/supported_decision_making_legal_capacity_and_guardianship2012final.pdf)

<sup>4</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

- information about what the NDIS is and how they can use it;
- support to understand and explore their options;
- support to identify personal goals and aspirations and how this relates to their support;
- identifying what type of supports are needed;
- selecting a preferred model of support and service provider;
- skills to self-manage and self-direct funding packages;
- consumer rights; and,
- how to speak up for yourself and negotiate with providers.

10. Information and training for people with disabilities about the NDIS must include the use of alternative and accessible communication formats and tools.

## **Human Rights Performance**

### ***The voice of people with disabilities – Convention on the Rights of Persons with Disabilities (CRPD) Article 4***

11. The ACT must urgently recognise and commit to its responsibility to fund independent individual advocacy for people with disabilities.
12. The ACT Government Directorates responsible for generating the highest demand for disability advocacy must contribute to its overall funding.
13. The ACT to facilitate consultations that are accessible to all people with disabilities so that they are central and have choice and control over all program and policy development concerning them. This includes people who need specific accommodations such as accessible communication formats and one to one direct consultations.
14. The ACT Government to meaningfully fund the full range of advocacy services in recognition of their critical role in ensuring self-determination, choice and control, for people with disabilities, particularly in regard to the imminent launch of the NDIS, which will increase the demand for advocacy.
15. The ACT must fund disability representative and advocacy organisations to consult with people with disabilities about the development of policies and services that concern them.
16. All work undertaken in the development and implementation of the National Disability Insurance Scheme at the ACT level must include people with disabilities, comprising at least 50 per cent of participants.

### ***Accommodation – Convention on the Rights of Persons with Disabilities (CRPD) Article 19***

17. The ACT must build public housing which is accessible or able to be modified to accommodate people with disabilities, and is in low density areas.
18. The ACT to develop accommodation options for people with disabilities, which are compliant with the United Nations *Convention on the Rights of Persons with Disabilities*, specifically Article 19.
19. Stop the redevelopment of ‘contemporary’ institutions that are segregated simulations of the larger congregate style accommodation they take as their precedents. They continue to segregate and isolate persons with disability from their non-disabled peers in contravention of Article 19 of CRPD.<sup>5</sup>

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<sup>5</sup> Shut In. (no date). *Shut In: Campaign to close institutions*. <http://www.shutin.org.au/>

20. The ACT must separate accommodation funding and support funding to enable people with disabilities to package their own accommodation and support arrangements according to their choice.
21. Expand support for people with disabilities to explore their accommodation options, preferences and choices.

***Freedom from Exploitation, Violence and Abuse – Convention on the Rights of Persons with Disabilities (CRPD) 16***

22. Urgently amend the *Domestic Violence and Protection Orders Act 2008* (ACT) to incorporate the NSW definition of household, which extends to people with disabilities living in various arrangements, to provide greater security for people with disabilities and enable better recognition and responses to the violence and abuse experienced by them in their homes.
23. Fund resources, supports, and mandatory training for disability organisations and support workers to recognise violence for what it is, and then to identify and respond appropriately to incidents of violence and abuse.

***Restrictive practices – Convention on the Rights of Persons with Disabilities (CRPD) 14 and 15***

24. Resource improved support for people with disabilities to prevent and reduce the use of restrictive practices, and eliminate inappropriate use of restrictive practices.
25. Resource the development of training and resources for disability support workers aimed at eliminating inappropriate use of restrictive practices and at eliminating and preventing the use of restrictive practices generally.
26. Develop independent statutory functions, as done in Victoria for the Official Visitor, to systematically collect and analyse data on restrictive practices across all disability service providers in the ACT to monitor the use of restrictive practices and produce information that will contribute to developing policy and practice aimed at reducing and preventing restrictive practices and eliminating their inappropriate use in the ACT and nationally.

***Respect for the home and family – Convention on the Rights of Persons with Disabilities (CRPD) 23***

27. Advocacy for Inclusion reiterates its recommendations of 2009, 2010 and 2012 - the ACT Government must establish comprehensive and intensive parenting and family support measures for families headed by parents with disability aimed at keeping children in the care of their birth parents. Programs must:
  - include long-term and home-based supports;
  - be flexible and sensitive to the needs of parents with disabilities;
  - be family-centred;
  - be strengths-based; and,
  - be prevention focused.
28. Fund mandatory human rights based disability awareness training for Care and Protection Services workers.
29. Fund the development of peer support groups for parents with disabilities.

***Employment – Convention on the Rights of Persons with Disabilities (CRPD) 27***

30. The ACT to undertake sector development to improve the accessibility, accommodations and supports for employment of people with disabilities in the public sector, including the development of meaningful positions targeted at people with disabilities.

31. The ACT to develop programs aimed at raising community awareness of the benefits of employing people with disabilities.
32. Increase funding to career and post school options programs for young people with disabilities to start in the early years of high school.
33. All employment programs funded and supported by the ACT Government must be human rights-based instead of punitive.
34. The ACT to cease funding of segregated work places and instead apply these funds to resourcing mainstream work places to accommodate people with disabilities, including in both open and supported positions, for proper pay.
35. As a member of COAG, the ACT advocate for reforms in federal employment programs to improve support for people with disabilities, including those who are already employed, to find and apply for jobs, and undertake career development and changes.

### ***Access to Justice – Convention on the Rights of Persons with Disabilities (CRPD) 13***

36. The ACT to investigate the Parkville College model of education with a view to implement such a program at Bimberi Youth Justice Centre targeted at reducing recidivism and successful restoration of young people with disabilities into the community.
37. The ACT to significantly increase funding for speech therapy for children and adults with disabilities with a view to improve their independence and inclusion in the community, and as part of an initiative to address the overrepresentation of people with disabilities in the criminal justice system.
38. The ACT must fund Community Legal Centres and Legal Advocacy to improve legal representation and support for people with disabilities.<sup>6</sup>
39. The ACT to ensure funding is adequate for people with disabilities to undertake human rights complaints via an independent body.
40. The ACT to research and develop mechanisms through which all people with disabilities, particularly those with cognitive and communication disabilities, are supported to give evidence and be heard in court on an equal basis to people without disabilities.
41. The ACT to undertake an audit of legislation to identify and address the barriers for people with disabilities to access justice.
42. Fund mandatory training for workers in the legal system aimed at promoting skills and understanding of how to respect the rights of people with disabilities and be sensitive to their needs at all stages of legal proceedings both inside and outside of court.
43. The ACT to provide supports for people with disabilities to access justice as a fundamental right and necessity, in the same way interpreter services are regarded for people who do not speak English well.

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<sup>6</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

### 3. Government Commitments

#### *The National Disability Strategy 2010-2020*

The *National Disability Strategy* (NDS) is a whole of government initiative that guides social policy to promote social inclusion and the potential of people with disabilities. It is a national strategy that “will help ensure that the principles underpinning the CRPD [*Convention on the Rights of Persons with Disabilities*] are incorporated into policies and programs affecting people with disability, their families and carers.” The ACT government is a party to this document, as part of COAG, and is obliged to follow through with the commitments and actions identified in it.

The *National Disability Strategy* is based on the social model of disability, which emphasises the importance of the social interactions and social constructions of disability in the way that disability is experienced by the individual and the community. The person’s disability does not necessarily cause the barriers, rather social attitudes, practices and structures are significant factors that inhibit a person’s full participation in the community. This is contrary to the historic medical model of disability, which is focused narrowly on the medical diagnoses and physiological deficits of the person, with the added expectation that they should be responsible for addressing those deficits.

In using the social model of disability the *National Disability Strategy* is concerned with ongoing discrimination and lack of social inclusion for people with disabilities and outlines the following policy directions for people with disabilities that all governments have committed to:

1. *Inclusive and accessible communities;*
2. *Rights protection, justice and legislation;*
3. *Economic security;*
4. *Personal and community support;*
5. *Learning and skills;*
6. *Health and wellbeing.*<sup>7</sup>

Under this strategy governments are committed to supporting people with disabilities to be central to the design, funding, delivery and evaluation of policies and services that affect them.

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<sup>7</sup> Commonwealth of Australia. (2011). *National Disability Strategy: An initiative of the Council of Australian Governments*. Canberra: Author.

## ***Future Directions 2009-2014***

The ACT Government is committed to the vision that: “All people with disabilities achieve what they want to achieve, live how they choose to live and are valued as full and equal members of the ACT community”<sup>8</sup>  
The Disability ACT strategic priorities for 2009-2014 are:

1. *I want the right support, right time, right place;*
2. *I want to contribute to the community;*
3. *I want to socialise and engage in the community;*
4. *I want to know what I need to know;*
5. *I want to tell my story once;*
6. *I want a quality service system.*<sup>9</sup>

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<sup>8</sup> Community Services Directorate. (2011). Disability ACT *Vision and values statement*. Retrieved from [http://www.dhcs.act.gov.au/disability\\_act/vision\\_and\\_values](http://www.dhcs.act.gov.au/disability_act/vision_and_values)

<sup>9</sup> Department of Housing and Community Services (now Community Services Directorate). (2009). *Future directions: towards challenge 2014*.

#### 4. Community Attitudes and Inclusion

The ACT has the following obligations:

- The *National Disability Strategy* is based on the social model of disability, which recognises that: *Attitudes practices and structures are disabling and can prevent people from enjoying economic participation, social inclusion and equality. This is not an inevitable result of an individual's impairment.*

The *Strategy* commits governments to: *Increase awareness and acceptance of the rights of people with disability (Policy direction 2.1)*

*Remove societal barriers preventing people with disability from participating as equal citizens (Policy direction 2.2)*

- Disability ACT *Future Directions* strategic priorities call for action targeted at changing community attitudes to promote inclusion, including:

2. *I want to contribute to the community; and*
3. *I want to socialise and engage in the community.*<sup>10</sup>

- The ACT *Disability Services Act 1991* states that: *Programs and services should be designed and administered so as to promote recognition of the competence of, and enhance the image of, people with disabilities.*

Community attitudes present the most significant barriers for people with disabilities and improving these must be a driving principle for all public policy concerning people with disabilities. Advocacy for Inclusion's work is centred on the impacts of community attitudes towards people with disabilities. People with disabilities are emerging from a long history of institutionalisation, segregation, discriminatory policies and laws, such as those based on eugenics, while people with disabilities continue to face exclusion and discrimination.

A recent survey by Scope and Deakin University of 761 Australians with disabilities revealed:

- 94 per cent do not have their need for meaningful participation in their community met;
- 90 per cent do not have their need for access to services met;
- 90 per cent do not have their need to feel valued and to belong met;
- 91 per cent do not have their need for social contact and support met.<sup>11</sup>

Community attitudes were the most commonly identified area for improvement to increase social inclusion (39 per cent).

In the ACT policies and practices continue to separate people with disabilities from the community through measures such as:

- Disability Employment Enterprises. This is a modern term for "sheltered workshops." They are workplaces where people with disabilities are segregated from the community.
- Special schools. This is where children with disabilities are segregated from other children to receive education.
- Disability specific accommodation. This includes community based supported accommodation such as group homes. Tenants in these homes often live in arrangements that are largely directed by the

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<sup>10</sup> Department of Housing and Community Services (now Community Services Directorate). (2009). As above.

<sup>11</sup> Scope & Deakin University. (2013). *Australians fail social inclusion test for people with a disability*. <http://ahha.asn.au/news/australians-fail-social-inclusion-test-people-disability>

service provider and operate as a 'workplace' similar to traditional large institutions. Many people living in these arrangements have minimal involvement in the wider community and remain isolated and excluded. This is why they are referred to as 'mini-institutions'.<sup>12</sup>

- Inaccessible public buildings and resources. This includes transport, community services, private housing and businesses such as restaurants, which are often physically inaccessible for people with disabilities. This excludes people with disabilities from the community.

Through these programs and barriers, people with disabilities are excluded from the community, often for their whole lives. The ACT must actively move away from supporting these models towards inclusive, human rights compliant models such as accommodating people in inclusive workplaces and schools. This is an extremely important area for the ACT Government to consider and target as all other attempts to progress social policy for people with disabilities are hampered by underlying community attitudes.

**Recommendation 1: Improving the inclusion of people with disabilities must be the driving force behind all ACT public policy, including by targeting community attitudes and structures that exclude or segregate people with disabilities.**

**Recommendation 2: Allocate and provide the resources necessary for residents to move to individualised community based housing and support options which will support their inclusion and participation in the general community.**<sup>13</sup>

**Recommendation 3: The ACT to actively phase out systems and facilities that segregate people with disabilities from the community and increase supports and resources to support people with disabilities to live, work and be educated in the community. This should be done by halting further funding to segregated systems and instead divert it to supports and resources for inclusion.**

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<sup>12</sup> Goggin, G., & Newell, C. (2005). *Disability in Australia: Exposing a social apartheid*. Sydney: University of NSW Press Ltd.

<sup>13</sup> Shut In. (no date). Shut In: Campaign to close institutions. <http://www.shutin.org.au/>

## 5. Self Determination

The ACT Government must proactively support the self-determination of people with disabilities. The introduction of the National Disability Insurance Scheme (NDIS), which is targeted at improving choice and control for people with disabilities, raises this to an urgent imperative requiring immediate policy attention.

Self-determination is where a person has choice and control over their life and the decisions made in their life. Self-advocacy skills – the skills to be assertive and speak up for oneself – are an essential component of self-determination. The belief that all people with disabilities can learn the skills to have a degree of choice and control over their own lives is fundamental to promoting self-determination.<sup>14</sup> However, this ability is disbelieved and resisted among the community due to societal misconceptions.

Paternalistic attitudes among the community perpetuate the belief that people with disabilities are passive and cannot be the drivers of their own lives. Many members of the community, including those working in the disability sector, hold the misconception that people with significant disabilities cannot have self-determination.<sup>15</sup> This includes their closest family, carers and support workers. Some people with disabilities are surrounded by ‘doubters’, which directly discourages and blocks a person’s ability to self-advocate and exercise self-determination.

*For some people with disabilities, the years of isolation and exclusion have had a profound impact on self-worth and self-esteem.*<sup>16</sup>

Segregation from the community in institutional type settings such as group homes also deskills or prevents people with disabilities from learning the skills to self-advocate, to have choice and control, and engage in the wider community.

People with disabilities approach Advocacy for Inclusion because they have little or no meaningful control over their lives. They have never been able to choose where they live, who they live with, what activities they do during the day, what employment they undertake (if any), and even what food they eat. Some do not even realise that they can have a choice in these things. People with disabilities ask Advocacy for Inclusion “do I have the same rights as other people”<sup>17</sup>. They can see that their lives are different, and often make the assumption that the segregation, exclusion, boredom and demeaning treatment surrounding them is acceptable to the community and therefore must be accepted by them.

A recent Australian study involving almost 900 people with disabilities and their families shows that these experiences are not limited to consumers at Advocacy for Inclusion:

- 30% of respondents don’t make the majority of their own decisions and 24% are not receiving the help they need to speak up;
- 54% of respondents had no choice about who provided them with personal support and 24% do not receive the level of support they were told they could have.<sup>18</sup>

There is a chronic lack of resources for people with disabilities, which often do not meet the needs and goals of people with disabilities as confirmed by the Productivity Commission in its report *Disability Care and Support*.<sup>19</sup> Consequently people with disabilities have few options to choose from. Some people with disabilities have

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<sup>14</sup> Wehmeyer, M. (1998). Self-determination and individuals with significant disabilities: Examining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities*, 23(1), 5-16.

<sup>15</sup> Wehmeyer, M. (1998). As above.

<sup>16</sup> National People with Disabilities and Carer Council. (2009). Shut out: The experience of people with disabilities and their families in Australia. p. 7. [http://www.fahcsia.gov.au/sites/default/files/documents/05\\_2012/nds\\_report.pdf](http://www.fahcsia.gov.au/sites/default/files/documents/05_2012/nds_report.pdf).

<sup>17</sup> Quote from Self-advocacy student

<sup>18</sup> Williams, R., & Fidock, A. (2012). *Quantities of Life: Data from the Tellus Survey*. South Australia: Julia Farr Association Purple Orange.

<sup>19</sup> Productivity Commission. (2011). *Disability Care and Support*. Report no. 54. Canberra.

never learnt the skills to make decisions about their lives and to assert their will and preferences (self-advocate) in the same way that people without disabilities are expected and encouraged to.

Few in the Canberra community would be comfortable if they knew the real picture for people with disabilities, yet the segregation ensures it is so hidden that most people know nothing about it.

The ACT Government must target resources at supporting people with disabilities to develop and then retain their self-advocacy skills so that they can maximise their self-determination. The ACT Government must proactively support the human rights of people with disabilities across all facets of their lives.

Self-Advocacy training for people with disabilities is crucial in skilling people with disabilities to have self-determination. Advocacy for Inclusion is highly successful in delivering this training. However, in 2009 Advocacy for Inclusion recognised that people with disabilities learning self-advocacy skills need active ongoing support in order to sustain those skills. Many live with disabilities which act as a barrier to learning and retention of knowledge. To address this we developed Supporting Self-advocacy training so that the people around people with disabilities were as skilled as possible in ensuring that new found self-advocacy skills would be actively supported and therefore have a much higher likelihood of retention.<sup>20</sup>

Supporting Self-Advocacy programs target carers, support people and family members of people with disabilities. This training assists them to recognise the strengths and abilities of people with disabilities, and to support self-determination and self-advocacy. It also helps to challenge the negative perceptions of people with disabilities among the community. The few programs available in the ACT have been very well received by the community and should now be delivered more broadly in the lead up to the NDIS. While there has been substantial commitment by both ACT and Federal governments for training, restructuring and workforce development for disability services in the lead up to the NDIS; there has not been a similar level of commitment to prepare people with disabilities for the new world of choice and control. Without this commitment the NDIS is in danger of failing the very people it is designed to support.

**Recommendation 4: Any funding for training and development in the disability sector must be matched by funding for Self-advocacy and Supporting Self-advocacy training, especially in the lead up to and for the first decade of the NDIS.**

### ***Self Determination and Mental Health***

As part of the mental health budget, the ACT Government should increase funding for self-advocacy training for people with disabilities. Advocacy for Inclusion works with consumers who link the lack of choice and control in their life to having significant adverse impacts on their sense of wellbeing.

*There is now indisputable recognition that some of the major determinants of our mental health and wellbeing lie within the social and economic domains of our lives, and include social inclusion, having a valued social position, physical and psychological security, opportunity for self-determination and control over one's life and access to meaningful employment, education, income and housing.<sup>21</sup>*

Self-determination is an essential aspect of people feeling competent, successful and maintaining good mental and general health.<sup>22 23</sup> Studies have found that self-determination is linked to other positive life outcomes for people with disabilities, including increased independent living skills and better employment outcomes.<sup>24</sup>

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<sup>20</sup> Advocacy for Inclusion. (2012). *Developing Supporting Self-Advocacy training: Why and how*. Presentation to the world congress on guardianship, Melbourne.

[www.advocacyforinclusion.org/index.php?option=com\\_content&view=category&layout=blog&id=48&Itemid=59](http://www.advocacyforinclusion.org/index.php?option=com_content&view=category&layout=blog&id=48&Itemid=59)

<sup>21</sup> Victorian Government Department of Human Services. (2005). *Evidence-based mental health promotion resource*. [http://www.health.vic.gov.au/healthpromotion/downloads/mental\\_health\\_resource.pdf](http://www.health.vic.gov.au/healthpromotion/downloads/mental_health_resource.pdf)

<sup>22</sup> American Psychological Association. (2004). *Increasing student success through instruction in self-determination*. <http://www.apa.org/research/action/success.aspx>

<sup>23</sup> Ryan, R., Patrick, H., Deci, E., & Williams, G. (2008). Facilitating health behaviour change and its maintenance: Interventions based on Self-Determination Theory. *The European Health Psychologist, Volume 10*

The Australian Institute of Health and Welfare (AIHW) reports alarming rates of mental health problems among people with disabilities:

- Almost half (48%) of people aged under 65 years with severe or profound disabilities had mental health problems, compared to 6% of people without disabilities;
- Of people aged 16–64 years with severe or profound disabilities, 42% had seriously thought about committing suicide, including 18% who had attempted suicide. This is in contrast to much lower proportions for people without disabilities (9% and 1% respectively).<sup>25</sup>

Mental illness among people with disabilities has been highlighted as an unmet need in Australia with Dr Maria Tomasic, President of The Royal Australian and New Zealand College of Psychiatrists acknowledging that “people with both intellectual disabilities and a mental illness often fall through the service gaps between the health and disability systems and their considerable needs are not addressed.”<sup>26</sup>

The 2013-14 budget will include \$500,000 in growth funding for mental health for the community sector. Some of this growth funding must be targeted at community mental health services that are appropriate for people with disabilities. One target area must be building self-determination of people with disabilities through self-advocacy training and support, particularly for those living in institutional settings.

Developing and encouraging the self-advocacy skills of people with disabilities is an essential component of self-determination. To be self-determined requires the capacity to speak up on your own behalf about goals, aspirations, choices, and preferences. Advocacy for Inclusion Self-advocacy students report feelings of being better able to speak up for themselves and through this have more choice and control in their lives.

Just as better self-determination and self-advocacy will support a better NDIS, it will also support greater mental health and wellbeing outcomes for people with disabilities. It is now time for the mental health budget to recognise and respond to the very high levels of mental illness in people with disabilities. Advocacy for Inclusion raised this in 2011 for the 2012-13 budget and it continues to require urgent attention.

**Recommendation 4: Any funding for training and development in the disability sector must be matched by funding for Self-advocacy and Supporting Self-advocacy training, especially in the lead up to and for the first decade of the NDIS.**

**Recommendation 5: The ACT to allocate 10% of the Mental Health budget growth funding, over the forward estimates, to targeted disability self-determination services as part of the response to reducing the high rates of mental illness among people with disabilities.**

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<sup>24</sup> Wehmeyer, M. L. (1997). Self-determination as an educational outcome. A definitional framework and implications for intervention. *Journal of Developmental and Physical Disabilities*, 9, 175-209.

<sup>25</sup> Australian Institute of Health and Welfare. (2010). *Health of Australians with disability: health status and risk factors*. Bulletin no. 83. Cat. no. AUS 132. Canberra: Author.

<sup>26</sup> Royal Australian and New Zealand College of Psychiatrists (accessed 25/8/11). *Intellectual disability mental illness is an unmet need* <http://www.ranzcp.org/latest-news/intellectual-disability-mental-illness-is-an-unmet-need.html>

## 6. Supported Decision Making

The ACT Government has the following commitments in regards to Supported Decision Making:

- Article 12 of the *Convention on the Rights of Persons with Disabilities* (CRPD):
  1. *States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.*
  2. *States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*
  3. *States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*<sup>27</sup>
- The *National Disability Strategy* stipulates that restrictive legislation must be reviewed from a human rights perspective.
- ACT Government is committed to the vision that: *All people with disabilities achieve what they want to achieve, live how they choose to live and are valued as full and equal members of the ACT community.*
- Section 8 (1) of the ACT *Human Rights Act 2004*: *Everyone has the right to recognition as a person before the law.*
- ACT *Disability Services Act 1991*: *People with disabilities have the same right as other members of society to make and actively participate in the decisions that affect their lives and are entitled to appropriate and necessary support to enable participation in, direction and implementation of the decisions that affect their lives.*

To fulfil these commitments the ACT Government must review the *Guardianship and Management of Property Act* and develop Supported Decision Making models as the alternative to guardianship practices. People with disabilities have historically been excluded from community and political discussions, including about matters directly concerning them. Despite the commitments above, this continues to be the case in the ACT with the use of guardianship law. Under CRPD Article 12, people with disabilities are presumed to have capacity but in reality they are often presumed not to have capacity.

Under guardianship law many people with cognitive disabilities are found to have legal incapacity, which removes recognition of an individual's decisions in the eyes of the law. The person with disability is then assigned a substitute decision maker, who makes decisions on that person's behalf. They are effectively placed in a "civil coma".<sup>28</sup> In sharp contrast, Article 12 of the CRPD states that it is an absolute right for people with disabilities to enjoy equal recognition and legal capacity before the law, and to access support to do so. As a signatory to the CRPD, Australia and therefore the ACT<sup>29</sup>, is obliged to substantially reconsider guardianship approaches.

Supported Decision Making is a relatively new model for supporting people with cognitive disabilities to make significant decisions, exercise their legal capacity, and retain and build decision making skills. It involves consultations where specific decisions are addressed, weighed, and concluded by an individual with disability. They do this with support from either a selected network of trusted and unpaid people or an individual such as a friend, family member or a volunteer. These supporters help the person with disability to gather and consider information about significant decisions. They help the person to weigh up the pros and cons of decisions as well as the likely outcomes and consequences. Finally the person makes their decision for themselves. This supports their self-determination.

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<sup>27</sup> United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. <http://www2.ohchr.org/english/law/disabilities-convention.htm>

<sup>28</sup> Mental Disability Advocacy Center. (2011). *Legal Capacity*. Retrieved from <http://www.mdac.info/en/legal-capacity>

<sup>29</sup> The ACT is obliged to implement the CRPD through Australia's ratification, but also through S 8 of the ACT *Human Rights Act*.

The broader community use Supported Decision Making daily, for example when making major life decisions most people will consult with family, partner, and/or friends for advice or greater knowledge. People with disabilities are not afforded this network of supports, rather they are expected to either act alone or, if they cannot, they are deemed “incapable” and placed under guardianship arrangements.

Supported Decision Making agreements are currently used in parts of Canada, the UK, and have been successfully trialled in South Australia.<sup>30</sup> The South Australian Office of the Public Advocate (OPA) evaluation highlights the benefits and successes of supported decision making agreements as an alternative to guardianship in the Australian context, including increased skills and confidence in decision making.<sup>31</sup> The ACT Government should fund the development of a supported decision making trial in the ACT as part of the suite of activities to support self-determination in the lead up to the launch of the NDIS.

**Recommendation 6: The ACT to fund the development of a Supported Decision Making trial in the ACT as part of the suite of activities to support choice and control of people with disabilities in the lead up to the launch of the NDIS, with the view to expand Supported Decision Making as an alternative to Guardianship.**

Guardianship is becoming widely recognised as out dated,<sup>32 33 34</sup> with the emphasis shifting from people with disabilities as passive service recipients to supporting them to be active members of the community.<sup>35</sup> It was clearly established during the review of the ACT *Mental Health (Treatment and Care) Act*, which also covers arrangements for many people with disabilities, that the progressive notions of Supported Decision Making coming into the new Act will directly contradict the *Guardianship and Management of Property Act*. All new structures that recognise Supported Decision Making will contradict current guardianship law, which does not recognise Supported Decision Making. It is pertinent that the ACT keeps up with these developments and reviews the guardianship law accordingly.

The NDIS is intended to set the scene for person-centred and self-determined support models that enable people with disabilities to “fulfil their potential as equal citizens.”<sup>36</sup> Standing as the largest reform to disability in a lifetime, the NDIS must be human rights compliant if it is to become a sustainable, relevant and workable scheme into the future, and to meet the Territory’s obligations. Supported Decision Making must become recognised by the ACT as a matter of urgency to support the choice and control of people with disabilities over their own lives.

Some informal Supported Decision Making practices are already in place in the ACT;<sup>37</sup> however, they operate within the dominant culture of guardianship, which does not recognise Supported Decision Making frameworks. This prevents the use of Supported Decision Making as an alternative to guardianship. When people with disabilities, carers, or other agencies believe that decision making arrangements are needed, guardianship is currently the only option. Guardianship, however, should only ever be used as a last resort after all other less restrictive options, including Supported Decision Making, have been tried and exhausted.

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<sup>30</sup> Advocacy for Inclusion. (2012). *Supported Decision Making, legal capacity and guardianship*. [http://www.advocacyforinclusion.org/publications/supported\\_decision\\_making\\_legal\\_capacity\\_and\\_guardianship2012final.pdf](http://www.advocacyforinclusion.org/publications/supported_decision_making_legal_capacity_and_guardianship2012final.pdf)

<sup>31</sup> Wallace, M. (2012). *Evaluation of the supported decision making framework: office of the Public Advocate*. Retrieved from [http://www.opa.sa.gov.au/documents/11\\_Supported%20Decision%20Making/8-Final%20Supported%20Decision%20Making%20Evaluation.pdf](http://www.opa.sa.gov.au/documents/11_Supported%20Decision%20Making/8-Final%20Supported%20Decision%20Making%20Evaluation.pdf)

<sup>32</sup> *Essential Principles: Irish Legal Capacity Law*. (2012). [http://www.nuigalway.ie/cdlp/documents/principles\\_web.pdf](http://www.nuigalway.ie/cdlp/documents/principles_web.pdf)

<sup>33</sup> Inclusion Europe. (2008). *Key Elements of a System for Supported Decision Making*. [http://inclusion-europe.org/images/stories/documents/PositionPapers/Position\\_Supported\\_Decision\\_Making\\_EN.pdf](http://inclusion-europe.org/images/stories/documents/PositionPapers/Position_Supported_Decision_Making_EN.pdf)

<sup>34</sup> Victorian Law Reform Commission. (2012). *Guardianship: Final Report 24*, Melbourne

<sup>35</sup> Victorian Law Reform Commission. (2012). As above.

<sup>36</sup> Productivity Commission. (2011). *Disability Care and Support*. Report no. 54. Canberra.

<sup>37</sup> South Australian Office of the Public Advocate. (2011). *Developing a Model of Practice for Supported Decision Making*. South Australia

**Recommendation 7: Review the *Guardianship and Management of Property Act 1991 (ACT)* with a view to compliance with the ACT's obligations under the CRPD and in line with the recommendations of Advocacy for Inclusion's report, *Supported Decision Making, legal capacity and guardianship*.<sup>38</sup>**

**Recommendation 8: Undertake an audit of all ACT legislation to investigate the right of all people in all situations to equal recognition before the law; the audit should investigate the presumption of legal capacity for all people, and extend to those circumstances where support may be required for a person to exercise their legal capacity.<sup>39</sup>**

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<sup>38</sup> Advocacy for Inclusion. (2012). *Supported Decision Making, legal capacity and guardianship*.

[http://www.advocacyforinclusion.org/publications/supported\\_decision\\_making\\_legal\\_capacity\\_and\\_guardianship2012final.pdf](http://www.advocacyforinclusion.org/publications/supported_decision_making_legal_capacity_and_guardianship2012final.pdf)

<sup>39</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

## 7. National Disability Insurance Scheme Launch Site

### *Preparing for Self-directed Funding*

The ACT Government must target resources at equipping and supporting people with disabilities for the National Disability Insurance Scheme (NDIS) **to claim and exercise choice and control over their lives. This includes funding substantially increased disability advocacy to support consumer choice.** The NDIS is a major advance in the way people with disabilities are supported in Australia. FAHCSIA states that it “will turn the way we currently provide disability services on its head.”<sup>40</sup> “Against an historical background of lack of choice and control, substantial capacity building and support will be required for many people with disabilities and their families.”<sup>41</sup> The most marginalised and silenced people will require particular preparation and supports to have choice and control, otherwise the NDIS will overlook them and fail to address their needs.

The NDIS will roll out in the ACT in July 2014. The ACT is enhancing disability services from July 2013 to prepare for the NDIS. “The Commonwealth Government has committed \$10.6 million for enhanced services and NDIS readiness in the ACT, as well as \$12 million to be spent in the ACT on sector development.”<sup>42</sup>

The Productivity Commission’s report into *Disability Care and Support* expresses a clear view that the NDIS funding should be based on a self-directed model in which people with disabilities carry a large part of the choice and control about what supports are put in place and who will deliver them.<sup>43</sup> Otherwise, the report says, it will simply result in the retention of the existing system with more funds.

*Consumer choice also generally leads to more efficient outcomes, as people are usually better placed to know what would meet their needs than service providers... the lack of choice adds to inefficiency in the current disability support system.*<sup>44</sup>

This clearly reflects the intention of Article 3 of the CRPD which calls for “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”.<sup>45</sup>

Some people with disabilities will **self-manage** their support packages. This option places all responsibility on the person with disability to manage the funds, organise the recruiting and training of staff, and take care of the administration. People with disabilities who have the desire and ability to self-manage their packages but have never had the experience will need training and support to develop the knowledge and skills necessary to manage their funds.

Many people with disabilities are expected to prefer to **self-direct** their support packages. Using this option the person with disability will choose an agency or person to manage their funds for them, who will then hire and roster staff and source other aids and equipment. The person with disability will have the **choice and control** over how they want their funds to be allocated and the chosen person or agency will administer and implement those decisions for them. Using principles of self-determination, all people with disabilities have the ability to **self-direct** their funds to some extent. Many Advocacy for Inclusion consumers and students describe a serious lack of self-determination in their lives but they also demonstrate their ability to exercise direction over their lives when they are skilled and supported to do so through self-advocacy training or self-advocacy supports.

A system for self-directed funding such as the NDIS is a means to an end, not an end in itself.<sup>46</sup> The NDIS Tier 3 target group of people with disabilities includes people whose lives are substantially organised and directed

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<sup>40</sup> FAHCSIA. (2013). *What is an NDIS?*. Retrieved from <http://www.ndis.gov.au/about-an-ndis/what-is-an-ndis/>

<sup>41</sup> Productivity Commission. (2011). As above.

<sup>42</sup> Community Services Directorate. (2013). *National Disability Insurance Scheme*.

[http://www.dhcs.act.gov.au/disability\\_act/national\\_disability\\_insurance\\_scheme](http://www.dhcs.act.gov.au/disability_act/national_disability_insurance_scheme)

<sup>43</sup> Productivity Commission. (2011). *Disability Care and Support*. Report no. 54. Canberra. p. 10.

<sup>44</sup> Productivity Commission. (2011). As above. p. 151

<sup>45</sup> United Nations. (2006). *Convention on the Rights of Persons with Disabilities*.

by other people, and who have little or no current skills in self-advocacy and making choices, including people under guardianship orders. Most people with disabilities have never had experience with their own funding package because it is such a major change from traditional funding systems.<sup>47 48 49</sup>

Advocacy for Inclusion is concerned that people with disabilities will not necessarily have more choice and control when the NDIS is rolled out when they do not have the experience, skills or support to have direction over their funds, negotiate, or assert their decisions. For example, Bach<sup>50</sup> found in his study that some people who received individualised funding did not gain control or self-determination over their support as service providers and support people continued to control the funds. Some people were not even aware that they had individualised funding.

The ACT Government must target resources at equipping and supporting people with disabilities **to claim and exercise the choice and control** intended by the NDIS to improve cost efficiency of the system and compliance with Article 3 of the CRPD.

In 2012 Advocacy for Inclusion was granted funding by the ACT Government to undertake research to help prepare people with disabilities for the NDIS. The study explored how much choice and control people with disabilities have in their lives, particularly over their support. The majority of research participants are expected to be Tier 3 NDIS recipients. Preliminary findings indicate:

- Many have never heard of the NDIS and do not know what it is;
- Many are unaware or unsure of how their current supports are funded and arranged;
- People with disabilities describe having minimal control over their supports including what service they use, where, when and how they are supported, and who supports them;
- Some people with disabilities are unsure what it means to have choice and control over their supports;
- Some feel that they would never be *allowed* to have choice and control over certain aspects of their support even if they wanted to;
- Some people with disabilities describe the control other people have over their lives such as service providers, support people, carers and/or family members. As shown in Bach's study,<sup>51</sup> this may not change when the NDIS is introduced if control continues to be held by the people around people with disabilities;
- Some people with disabilities are surrounded by 'doubters' who do not view the person with disability as having a valid or meaningful opinion, and/or who doubt the person's ability to achieve goals or make worthwhile decisions;

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<sup>46</sup> Largay, C. (2002). Individualised funding in disability services. In T. Eardley & B. Bradbury (Eds.), *Competing visions: Proceedings of the national social policy conference, Sydney 4-6 July 2001*.

<sup>47</sup> Aboriginal Disability Network NSW. (2012). *Living life my way: Consultations with Aboriginal communities final report*. Retrieved from [http://www.adhc.nsw.gov.au/\\_data/assets/file/0008/255671/1234\\_ADHC\\_PCA-Aboriginal\\_ConsultationReport\\_WEB.pdf](http://www.adhc.nsw.gov.au/_data/assets/file/0008/255671/1234_ADHC_PCA-Aboriginal_ConsultationReport_WEB.pdf)

<sup>48</sup> Largay, C. (2002). As above.

<sup>49</sup> Largay, C., & Ottmann, G. (2011). Towards a Framework for Implementing Individual Funding Based on an Australian Case Study. *Journal of Policy and Practice in Intellectual Disabilities*, 8(1), 18–27.

<sup>50</sup> Bach, M. (2000). Individualised funding and self-determination: making sure the means does not become the end. Unpublished paper presented at *First International Conference on Self-determination and Individualised Funding*. Seattle, USA. <http://members.home.net/directfunding/Materials.htm>.

<sup>51</sup> Bach, M. (2000). Individualised funding and self-determination: making sure the means does not become the end. Unpublished paper presented at *First International Conference on Self-determination and Individualised Funding*. Seattle, USA. <http://members.home.net/directfunding/Materials.htm>.

- People with disabilities can identify the importance of people in their life who support them to navigate the disability support system, who encourage and help them to make informed decisions, and who have positive attitudes towards the person's ability and perspectives;
- People with disabilities identify that support and training to stand-up for themselves is important in having choice and control.

Work must start immediately on building the self-advocacy and decision making capacity of people with disabilities in preparation for the NDIS. Particular attention must be applied to those who are most unengaged<sup>52</sup> and disempowered to be at the forefront of any work in preparation for the NDIS.

Preparation for many people in the Tier 3 target group will need to be more involved than simply providing information about the NDIS. Many will need intensive, practical and ongoing supports, especially those who do not learn well via conventional "class room" style teaching, and those who may need ongoing reinforcement of newly learned skills. Some people with disabilities will require information provision in alternative communication formats in order to communicate their wishes and to have as much choice and control over their funds as possible; for example, the use of new technologies such as iPads and communication cards.

**Recommendation 9: The ACT must fund independent non-service organisations to provide training, mentoring and support for people with disabilities to prepare for the NDIS including:**

- the basics of money and budgeting;
- information about what the NDIS is and how they can use it;
- support to understand and explore their options;
- support to identify personal goals and aspirations and how this relates to their support;
- identifying what type of supports are needed;
- selecting a preferred model of support and service provider;
- skills to self-manage and self-direct funding packages;
- consumer rights; and,
- how to speak up for yourself and negotiate with providers.

**Recommendation 10: Information and training for people with disabilities about the NDIS must include the use of alternative and accessible communication formats and tools.**

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<sup>52</sup> The term "unengaged" is used to apply to people who have never had an opportunity to be engaged, as opposed to "disengaged" which implies a former level of engagement that no longer exists.

## 8. Human Rights Performance

Australia has ratified the *Convention on the Rights of Persons with Disabilities* (CRPD), accompanied in the ACT by the *Human Rights Act 2004*. Both of these instruments commit the ACT Government to protect and promote the human rights of people with disabilities. The *National Disability Strategy* makes governments responsible at all levels to ensure that the principles of the CRPD are incorporated into policies and programs affecting people with disabilities.

### ***The voice of people with disabilities – Convention on the Rights of Persons with Disabilities (CRPD)*** **Article 4**

- As a signatory to the CRPD, under Article 4 Australian governments are obliged to:  
*In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.*
- The *National Disability Strategy* recognises that: *Disability advocacy enables people with disability to actively participate in the decision-making processes that safeguard and advance their human rights, wellbeing and interests.*

The *Strategy* commits governments to: *Support independent advocacy to protect the rights of people with disability (Areas for Future Action 2.11).*

- Disability ACT strategic priorities states: *I want a service system that continuously improves by asking me if it provides programs that suit my life and goals (Future Directions Strategic Priority 6).*
- The ACT *Disability Services Act 1991* stipulates that:  
*Services should be designed and administered so as to ensure that people with disabilities have access to advocacy support where necessary to ensure adequate participation in decision making about the services they receive.*

The ACT Government must improve consultation with and advocacy support for people with disabilities to ensure that their voice is heard on policy and service matters directly concerning them. There is high demand for advocacy support in Australia and despite this and the above commitments, independent disability advocacy organisations are severely underfunded.<sup>53</sup> The NDIS will create increased demand for independent disability advocacy services. The ACT must urgently fund substantially increased capacity for advocacy services to cater for the predicted increase in service users, to support consumer choice and assist them to navigate a new system.

Policy makers and community workers often assume that people with disabilities have parents, carers or guardians who will speak up on their behalf and make decisions for them. This is often not the case and regardless is inappropriate as these groups have different interests. This assumption does not recognise the self-determination of people with disabilities. Independent disability advocacy must expand with the expanding disability sector coming with the NDIS. The Productivity Commission advised that:

Individual and systemic advocacy should continue to play an important role in the disability sector under the NDIS, and should be sufficiently funded to do so. In order to ensure its independence (from the NDIA) and effective provision, advocacy should be funded by FaHCSIA and from state and territory governments.<sup>54</sup>

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<sup>53</sup>CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

<sup>54</sup> Productivity Commission. (2011). *Disability Care and Support*. Report no. 54. Canberra. p. 471

The ACT Government is one of only two jurisdictions in Australia that do not currently fund individual advocacy for people with disabilities. **Since January 2012 Advocacy for Inclusion has had to decline more than twice as many individual advocacy intakes as it has accepted because of this limited capacity.** “DANA [Disability Advocacy Network Australia] contends that it is appropriate for the level of government responsible for each service system to acknowledge the role of advocacy within their system and contribute to the pool of funding for independent disability advocacy accordingly.”<sup>55</sup>

The continuing lack of funding is unacceptable and contradicts the clear ACT Government obligations under the *Disability Services Act 1991*, the CRPD, the *National Disability Strategy* and the *Future Directions Strategic Priorities*.

**Recommendation 11: The ACT must urgently recognise and commit to its responsibility to fund independent individual advocacy for people with disabilities.**

The demand for advocacy is created by disability services which are funded by Disability ACT. Additionally, high demand is created by:

- Care and protection
- Accommodation
- Community safety and justice
- Education
- Employment

Yet none of these systems contribute to disability advocacy provision in the ACT.

**Recommendation 12: The ACT Government Directorates responsible for generating the highest demand for disability advocacy must contribute to its overall funding.**

People with disabilities have historically been excluded from community and political discussions, including about matters directly concerning them. This continues to be the case, with most consultations focusing on carers and service providers, who are much easier to consult, but who have different interests and perspectives to people with disabilities. The *CRPD Civil Society Report* recommends that governments should develop robust mechanisms for engagement with people with disabilities, including through their representative organisations, to ensure meaningful involvement in all stages of the planning and implementation of policies concerning people with disabilities. Such consultation is lacking and current efforts are tokenistic.<sup>56</sup>

Traditional consultation formats are often inaccessible or inappropriate, such as community forums, particularly for the most isolated and silenced members of the community. Some people with disabilities need particular support and accommodations to be genuinely involved in consultations; for example, people with communication barriers or people who need more time and space to understand and make contributions, who may find direct one to one consultation more appropriate. The standard consulting period allowed by the ACT Government, i.e. 6 weeks, does not work for many people with disabilities as it doesn't for other members of the community. Longer timeframes must be allocated to enable people with disabilities to be involved.

**Recommendation 13: The ACT to facilitate consultations that are accessible to all people with disabilities so that they are central and have choice and control over all program and policy development concerning them. This includes people who need specific accommodations such as accessible communication formats and one to one direct consultations.**

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<sup>55</sup> DANA. (2013). *Submission to Australian Government Community Consultation 2013-14 Budget*. p. 17-18

<sup>56</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

The Productivity Commission's Report, *Disability Care and Support*,<sup>57</sup> highlights the major and costly consequences of this lack of meaningful engagement, including that the system is broken, offering little choice and control for people with disabilities, and leaving them without the support they need and want. These problems will continue to break the system down and waste money if people with disabilities are not actively involved in the planning and implementation, regardless of the new NDIS. Resources in the disability sector have minimal capacity and are currently applied to react to crisis rather than prevention and early intervention. Money will be saved when people with disabilities are consulted on how to allocate their resources so that fewer problems with service provision arise later on.

Independent advocacy is a key design feature of all disability service systems. It will ultimately not be possible for service systems to appropriately target their services without advocacy support and representation being available to those most in need of services. Nor will it be possible for service systems to ensure comprehensive quality assurance and improvement processes are in place without the feedback loops created by individual and systemic advocacy practice.<sup>58</sup>

Without adequate advocacy resources services will not be properly informed and designed to suit the needs of people with disabilities. As noted by the *National Disability Strategy*, people with disabilities have a lived experience of disability; they must be supported to be the centre of consultation for policies and programs concerning them.<sup>59</sup> Independent disability advocacy organisations play a crucial role in this by providing several types of advocacy:

- **Individual advocacy** enables people with disabilities to provide feedback about the disability sector through intensive one on one support to raise and resolve service issues. The NDIS is a system that will allow people with disabilities to consider support arrangements that they have never been able to consider in the current inflexible service system. Individual advocacy will and must play a major role in supporting people to express their wishes in a new system, especially those most isolated and marginalised.
- **Self-advocacy** supports and trains people with disabilities to advocate on their own behalf.
- **Systemic advocacy** supports people with disabilities to collectively influence the service systems, legislation and structures concerning them. Advocacy organisations, as independent bodies, need to be funded to undertake consultation directly with people with disabilities in ways that are accessible and meaningful to them.
- **Legal advocacy** supports people with disabilities with the legal aspects of discrimination and other matters. This is highly important as many people with disabilities rely on service providers for a life-time and may encounter legal issues that are not covered by legal-aid. Due to the economic disadvantage of people with disabilities they are also less able to afford legal representation not subsidised by government.
- **Family advocacy** supports families to advocate on behalf of a person with disability.
- **Citizen advocacy** matches a person with disability with a volunteer who provides long-term advocacy support.

**Currently, the ACT Government only provides a small amount of ongoing funding for self-advocacy and some further funding for systemic advocacy. This shortfall in advocacy availability in the ACT must be addressed now.**

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<sup>57</sup> Productivity Commission. (2011). *Disability Care and Support*. Report no. 54. Canberra

<sup>58</sup> DANA. (2013). *Submission to Australian Government Community Consultation 2013-14 Budget*.

**Recommendation 14: The ACT Government to meaningfully fund the full range of advocacy services in recognition of their critical role in ensuring self-determination, choice and control for people with disabilities, particularly in regard to the imminent launch of the NDIS, which will increase the demand for advocacy.**

Advocacy organisations have close relationships with the most silenced members of the community and can be the vehicle through which people with disabilities feel safe to voice their perspective. For some, the support of an advocacy organisation may be the only way they can have their voice heard due to the often overpowering perspectives of carers and other service organisations. If the ACT Government is to provide person-centred services to people with disabilities as promised under Disability ACT's *Future Directions Strategic Priority 1*, it must resource people with disabilities to be directly consulted in the development of policies and services and give feedback through their representative and advocacy organisations.

**Recommendation 15: The ACT must fund disability representative and advocacy organisations to consult with people with disabilities about the development of policies and services that concern them.**

Any bodies which are established in the ACT to work towards the NDIS must comprise at least 50 per cent people with disabilities who are **connected** to a representative voice for their community. Where there is no current knowledge of appropriate people with disabilities representative organisations should be consulted about who might be appropriate.

**Recommendation 16: All work undertaken in the development and implementation of the National Disability Insurance Scheme at the ACT level must include people with disabilities, comprising at least 50 per cent of participants.**

## **Accommodation – Convention on the Rights of Persons with Disabilities (CRPD) Article 19**

- *Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement (CRPD Article 19).*
- The ACT Government has committed to Disability ACT strategic priority:
  1. *I want the right support, right time, right place (Future Directions Strategic Priority 1)*
- The *National Disability Strategy* commits all Australian governments to: *Improved provision of accessible and well-designed housing with choice for people with disability about where they live (Inclusive and accessible communities: Policy direction 3)*
- The ACT *Disability Services Act 1991* Schedule 2 (2) states: *Services should contribute to ensuring that the conditions of everyday life of people with disabilities are the same as, or as close as possible to, the conditions of everyday life enjoyed in the general community.*

The Shut In Campaign is a collaboration between advocacy organisations and people with disabilities. Shut In defines institutions as:

*Segregated accommodation or congregate care facilities that exist only to provide people with disability with social supports. These facilities can be called ‘cluster housing’, ‘villas’, ‘key-ring facilities’, ‘boarding houses’ or ‘group homes’. They have the effect of segregating and isolating people with disability from the community, of denying people with disability the same housing options as other people living in the community and of forcing people with disability to live together in order to receive social supports.<sup>60</sup>*

Many people with disabilities live in these institutional settings. The ACT Government must improve and restructure funding for support and accommodation for people with disabilities to promote their choice and control over their accommodation arrangements. In the ACT practices to support the above ACT commitments are grossly underdeveloped and many people with disabilities have no choice and control over their living arrangements.

There is a severe shortage of accommodation for people with disabilities in the ACT. The target waiting time for people on the priority Housing ACT waiting list is a maximum of 90 days. A number of consumers at Advocacy for Inclusion have waited for over 12 months on the priority list, often while they are homeless or living in unsafe situations. This is due to a shortage of accessible and appropriate homes for people with disabilities. This is unacceptable and constitutes systemic discrimination against people with disabilities.

### **Recommendation 17: The ACT must build public housing which is accessible or able to be modified to accommodate people with disabilities, and is in low density areas.**

It is not uncommon in the ACT for a person with disability to only live in a particular home with particular people because it is the only option that offers them the support they need. The *CRPD Civil Society Report* notes this as an issue, including group homes which are purpose built for people with disabilities.<sup>61</sup> “Many people with disabilities are effectively forced to live in institutions or residential care facilities in order to receive social and personal care supports.”<sup>62</sup> They would never live there otherwise and regularly express a desire to Advocacy for Inclusion to live in other settings. These models make “person-centred planning” and “choice and control” for people with disabilities impossible, which is a central concept to the NDIS and is included in the Disability ACT *Future Directions Strategic Priority 1*.

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<sup>60</sup> Shut In. (no date). *Information about institutions*. <http://www.shutin.org.au/>

<sup>61</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

<sup>62</sup> CRPD Civil Society. (2012). As above.

Accommodation and support are tightly entwined in the ACT disability sector. The ACT Government has recently committed to building two homes specifically to provide supported accommodation to 5 adults with disabilities in each home.<sup>63</sup> Combining accommodation and support into inseparable services does **NOT** offer choice and control to people with disabilities. People are being forced to opt to live in these arrangements only because it provides them with the support they need. The ACT Government is denying the right to choice and control of people with disabilities. This is unacceptable and is in contravention of CRPD Article 19 and the above Government commitments.

These combined support and accommodation models do not resemble “the conditions of everyday life enjoyed in the general community.”<sup>64</sup> In 2006 the Australian Bureau of Statistics (ABS) reported that only 10% of the population lived in a household of 5 or more persons.<sup>65</sup> If the general population mostly chooses not to live with 4 or more other adults, then why would people with disabilities be any more likely to choose such an arrangement? There is an expectation that these are the sorts of environments people with disabilities ought to be living in. This expectation must change. The ACT Government is obliged under CRPD Article 19 and the *Disability Services Act 1991*, to develop accommodation options that afford people with disabilities the same range of choices enjoyed by the general community.

Disability specific group homes accommodate between 2 to 6 people. Regardless of the number of residents living in the home, these homes operate as institutions. People with disabilities find themselves living in these homes because they are ‘placed’ there rather than because they have chosen to live there. This system must change.

**Recommendation 18: The ACT to develop accommodation options for people with disabilities, which are compliant with the United Nations *Convention on the Rights of Persons with Disabilities*, specifically Article 19.**

**Recommendation 19: Stop the redevelopment of ‘contemporary’ institutions that are segregated simulations of the larger congregate style accommodation they take as their precedents. They continue to segregate and isolate persons with disability from their non-disabled peers in contravention of Article 19 of CRPD.<sup>66</sup>**

Combined support and accommodation arrangements are widely directed by service providers and operate as workplaces rather than homes. Consumers with Advocacy for Inclusion living in these arrangements cannot have pets if they want to, they cannot choose what they have for dinner, and they cannot spontaneously go out. Instead, support workers decide if pets come to the home, a nutritionist makes up house-hold meal plans, support workers do the grocery shopping without consumers, and they live their lives on a regimented schedule made by the service provider in an attempt to accommodate all residents with the minimum of resources. Consumers cannot easily move home because the support is bound to the house. Some consumers have been waiting to move home for 5 or more years because of this. These are just a few examples of the institutional type operations within these homes and the limitations they place on the choice and control of people with disabilities.

**Accommodation funding and support funding for people with disabilities must be separated so that people can truly make a choice about where they want to live.** The roll out of the NDIS will support the separation of accommodation and support as many more people will have access to individualised supports. People will be less “trapped” in a home to which the support funding is bound. The ACT Government must

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<sup>63</sup> ACT Government. (2012). *Request for costing of election commitment*. [www.treasury.act.gov.au/electioncostings/documents/Labor/Requests/LAB083%20-%20Community%20Supported%20Disability%20Housing.pdf](http://www.treasury.act.gov.au/electioncostings/documents/Labor/Requests/LAB083%20-%20Community%20Supported%20Disability%20Housing.pdf)

<sup>64</sup> ACT *Disability Services Act 1991*

<sup>65</sup> ABS. (2012). Population: Households and families. *1301.0 Year Book Australia*. Retrieved from [www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1301.0~2012~Main%20Features~Households%20and%20families~56](http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1301.0~2012~Main%20Features~Households%20and%20families~56)

<sup>66</sup> Shut In. (no date). *Shut In: Campaign to close institutions*. <http://www.shutin.org.au/>

develop mechanisms to support this separation as part of a consistent and systematic approach for all people with disabilities seeking support and accommodation.

**Recommendation 20: The ACT must separate accommodation funding and support funding to enable people with disabilities to package their own accommodation and support arrangements according to their choice.**

The creation of a “Housing Options Facilitator” within Disability ACT is a positive development in the ACT, which has provided tools and guidance to people with disabilities to explore their options and convey their accommodation preferences. However, it is not solving the overall problem. Along with the separation of support from accommodation, these resources must be expanded so that all people with disabilities in the ACT are able to plan and implement their accommodation preferences. This more human rights compliant and inclusive model of supporting people with disabilities will prevent other social problems from arising such as violence between co-residents.

**Recommendation 21: Expand support for people with disabilities to explore their accommodation options, preferences and choices.**

## **Freedom from Exploitation, Violence and Abuse – Convention on the Rights of Persons with Disabilities (CRPD) 16**

The ACT has a number of commitments to promote the rights of people with disabilities to live free from abuse, violence and exploitation:

- *States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.* (CRPD Article 16)
- *The National Disability Strategy Policy Direction 2.4: People with disability to be safe from violence, exploitation and neglect.*

*The National Disability Strategy Areas for Future Action 2.3: Develop strategies to reduce violence, abuse and neglect of people with disability.*

- *Australia's National Plan to Reduce Violence against Women and their Children asserts that:*

*New perspectives and strategies are required by all Australian governments in the delivery of best responses, as early as possible to victims of violence. Women may require specialised support based on individual needs in recognition of issues such as age, English language proficiency, disability, sexuality and prior victimisation.*

The ACT Government must take immediate action to protect people with disabilities from violence and abuse. Studies show that people with disabilities experience higher rates of abuse and violence than people without disabilities.<sup>67 68 69</sup> "Research suggests high rates of violence, abuse and neglect of women and girls with disabilities in institutional settings. Such violence is experienced more often than men with disability in institutions. In these circumstances, women with disabilities may experience violence for longer periods of time due to inadequate pathways to safety, and may be afraid to report incidents for fear of reprisal or a lack of confidence in authorities and the justice system"<sup>70</sup>

Numerous cases at Advocacy for Inclusion reflect these concerns. Following public discussion in Canberra about violence in group homes,<sup>71</sup> Advocacy for Inclusion undertook an audit of our current advocacy cases. This showed that 25 per cent of all cases relate to violence in group homes and over 30 per cent of all cases relate to sexual violence or exploitation.

The types of violence experienced by people with disabilities include physical violence, sexual assault, verbal abuse, and living in fear of the threat of harm. Many live with intimidation, financial exploitation, and suffer retribution for decisions, choices or complaints they have made. People with disabilities face different forms of violence than people without disabilities. For example, forced and coerced sterilisation and abortion,<sup>72</sup> chemical restraint, withholding of aids and equipment, having services or activities withheld, continual belittling and demeaning treatment based on the disability, and threats to remove children.<sup>73</sup>

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<sup>67</sup> Powers, L., Curry, M., McNeff, E., Saxton, M., Powers, J., & Oschwald, M. (2008). End the silence: A survey of abuse against men with disabilities. *The Journal of Rehabilitation*, 77.4.

<sup>68</sup> Powers, L., Curry, M., Oschwald, M., & Maley, S. (2002). Barriers and strategies to addressing abuse: A survey of disabled women's experience. *The Journal of Rehabilitation*, 68(1).

<sup>69</sup> Hughes, R., Lund, E., Gabrielli, J., Curry, M., & Powers, E. (2011). Prevalence of interpersonal violence against community-living adults with disabilities: A literature review. *Rehabilitation Psychology*, 56(4), 302-319.

<sup>70</sup> Australian Human Rights Commission. (2012). *Independent interim report on CEDAW: Report to the committee on the elimination of all forms of discrimination against women*. [http://www2.ohchr.org/english/bodies/cedaw/docs/followup/ngos/AHRC\\_Australia.pdf](http://www2.ohchr.org/english/bodies/cedaw/docs/followup/ngos/AHRC_Australia.pdf)

<sup>71</sup> The Canberra Times. (14 September 2011). Tribunal ends assault nightmare for gentle giant. *The Canberra Times*. [www.canberratimes.com.au/act-news/tribunal-ends-assault-nightmare-for-gentle-giant-20110914-1wraf.html](http://www.canberratimes.com.au/act-news/tribunal-ends-assault-nightmare-for-gentle-giant-20110914-1wraf.html)

<sup>72</sup> Women with Disabilities Australia, 2011, *Sterilisation of Women and Girls with Disabilities - An update on the issue in Australia*, [www2.ohchr.org/english/bodies/cedaw/docs/cedaw\\_crc\\_contributions/WomenwithDisabilitiesAustralia.pdf](http://www2.ohchr.org/english/bodies/cedaw/docs/cedaw_crc_contributions/WomenwithDisabilitiesAustralia.pdf)

<sup>73</sup> Advocacy for Inclusion. (2011). Submission to ACT budget consultation 2012 – 2013.

Many people with disabilities are not even aware that what is happening to them is actually violence or abuse – they are conditioned and oppressed or are unaware of their rights. Compounding this is the fact that many of these forms of violence are not recognised as violence by the general community, statutory bodies and judicial systems. There is little in the way of legislative protections, programs and resources to support people with disabilities to be free from these issues. Unlike in NSW, the ACT *Domestic Violence and Protection Orders Act 2008* does not recognise the types of relationships that occur in disability group homes due to its narrow definition of ‘domestic relationships’. This means that people with disabilities are significantly excluded from the Act’s protections.<sup>74</sup> Because of this people with disabilities are not supported appropriately if at all to have co-resident perpetrators removed or to find alternative accommodation. This is a crucial and urgent point for change.

As in other domestic situations, violence also occurs in disability group homes. Many people with disabilities, particularly those in group homes and other institutional settings, live in an arrangement and with people not of their choosing. This results in conflict between house mates and escalates to violence.

### **Case study based on case studies at Advocacy for Inclusion (de-identified for privacy)**

Sasha was *placed* in a home with another adult whom he did not choose to live with, and whom he subsequently found he did not get along with. He was expected to “get along” and “behave yourself”.

After months of tension, such as verbal aggression and harassment between Sasha and the house mate, it escalated and reached crisis point when the house mate physically attacks him. They bite him, scratched him, hit him, and on one occasion almost broke his hand. He felt unsafe, uncomfortable and unwelcome in his own home. Sasha didn’t want to leave his bedroom and staff have installed a lock on the door so that he can get out but the house mate cannot get in.

This continued for many months as he experienced countless occasions where he was physically attacked and harmed by the house mate. Sometimes he retaliated and hit back. Support workers then administered prescribed drugs to “calm him down” as per agency protocol. This is known as chemical restraint.

Sasha cannot simply leave as he depends on the essential support provided in this home, and he does not know how to resource alternatives. It takes a lot of advocacy by his advocate to finally convince the service provider that this is more than just a “tiff”. Now the service provider says that it will take a while before another home can be found for him or his house mate. In the meantime the violence continues.

Because Sasha lives in a disability group home, which is not recognised by ACT Domestic Violence legislation, he is not afforded the same protections from violence in his home as people without disabilities. If his living arrangement was covered, the law would require a much more robust response, whereby the perpetrator would be removed and mechanisms put in place to keep him safe from that person. Instead, the violence is regarded as a ‘disability matter’ and the service provider is left to manage it at their own discretion.

**Recommendation 22: Urgently amend the *Domestic Violence and Protection Orders Act 2008* (ACT) to incorporate the NSW definition of household, which extends to people with disabilities living in various arrangements, to provide greater security for people with disabilities and enable better recognition and responses to the violence and abuse experienced by them in their homes.**

Many individual advocacy cases at Advocacy for Inclusion look just like this. These are not horror stories from another time or in another less developed country; they are the real experiences of violence and abuse happening here in the ACT. Advocacy for Inclusion finds that when people with disabilities with communication

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<sup>74</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

barriers are consistently denied choice and control, they eventually try to communicate their choices through acts of aggression and violence as they have lost all other options to get people to listen to them. The Victorian Office of the Senior Practitioner makes similar observations in their report on restrictive practices.<sup>75</sup> Advocacy for Inclusion has witnessed cases where a person's violence has ceased when they moved into alternative accommodation with house mates or alone, but according to their choice.

This violence would be considered domestic violence for people without disabilities and it should not be seen differently just because it involves people with disabilities. Queensland Advocacy Incorporated explains that this violence is a "structurally induced crime,"<sup>76</sup> created by living circumstances over which neither the victim nor the perpetrator have control. People with disabilities are often afraid to speak up as they fear that they will upset their service provider or their family. Others have significant communication barriers and these issues are overlooked.

Abuse and violence in group homes is recognised as an issue in other states. The 2011-2012 NSW Ombudsman Annual Report states that one of the main complaints about disability supported accommodation included those about abuse and assault between co-tenants.<sup>77</sup> It is also a major issue in the ACT but it remains poorly recognised. There is an urgent need for support and accommodation to be separated so that people with disabilities have greater choice and control over where they live, which will prevent issues of conflict and violence between housemates in supported accommodation.

**Recommendation 20: The ACT must separate accommodation funding and support funding to enable people with disabilities to package their own accommodation and support arrangements according to their choice.**

People living in residential care facilities designed specifically for people with particular behavioural support needs are at heightened risk of violence and abuse.<sup>78</sup> People, who experience communication barriers and subsequent behavioural difficulties, including violence, are congregated together in these facilities, creating a recipe for aggression, violence and abuse among the tenants and by support workers. This contributes to a "culture of violence" compounded by restrictive practices such as chemical restraint.<sup>79</sup> Some consumers who were once subject to frequent restrictive practices, such as chemical restraint, were no longer subject to these practices after moving into suitable accommodation.

Advocacy for Inclusion is shocked by the complacency towards violence among service providers. It seems to be systemically accepted. Disability support staff seem inured to it after years of having no alternative to offer, or perhaps have succumbed to a "culture of violence." Some studies show that supported accommodation facilities can harbour cultures that accept violence as a part of everyday life, wherein organisational staff feel unequipped and powerless to respond appropriately to incidents of abuse and violence, and also perpetrate violent behaviour themselves.<sup>80</sup> Research suggests this work culture and environment, and staff attitudes and awareness play critical roles in promoting the safety of tenants in supported accommodation.<sup>81</sup>

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<sup>75</sup> Ramcharan, P. Nankervis, K. Strong, M., & Robertson, A. (2009). *Experiences of restrictive practices: A view from people with disabilities and family carers: A final research report to the Office of the Senior Practitioner.*

[http://www.dhs.vic.gov.au/\\_\\_\\_data/assets/pdf\\_file/0008/608588/osp\\_experiencesofrestrictivepractices\\_pdf\\_0509.pdf](http://www.dhs.vic.gov.au/___data/assets/pdf_file/0008/608588/osp_experiencesofrestrictivepractices_pdf_0509.pdf)

<sup>76</sup> French, P. (2007). *Disabled justice: The barriers to justice for persons with disability in Queensland.* For Queensland Advocacy Incorporated.

<sup>77</sup> NSW Ombudsman. (2012). *NSW Ombudsman annual report 2011 – 2012.* [www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/nsw-ombudsman/nsw-ombudsman-annual-report-2011-2012](http://www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/nsw-ombudsman/nsw-ombudsman-annual-report-2011-2012)

<sup>78</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities.*

<sup>79</sup> CRPD Civil Society. (2012). As above.

<sup>80</sup> Strand, M. L., Benzein, E., & Saveman, B. (2004). Violence in the care of adult persons with intellectual disabilities. *Journal of Clinical Nursing*, 13, 506–514.

<sup>81</sup> Marsland, D., Oakes, P. White, C. (2007). Abuse in care? The identification of early indicators of the abuse of people with learning disabilities in residential settings. *The Journal of Adult Protection*, 9(4), 6-20.

There is no suggestion that any particular organisations, or their staff, don't care about violence, but rather they become unable to do anything about it and over time this has resulted in an "acceptance" that this is simply "how it is".

The lack of legislative recognition of the issue means that disability services have a great degree of discretion in deciding how to respond to issues of violence, exploitation and abuse of people with disabilities and whether to report it to the police.<sup>82</sup> This is deeply concerning given the "acceptance" among service providers of these issues. Incidents of abuse and violence are often not reported and are subsequently not investigated; they do not go beyond the administrative processes within the service provider.<sup>83</sup>

**Recommendation 23: Fund resources, supports, and mandatory training for disability organisations and support workers to recognise violence for what it is, and then to identify and respond appropriately to incidents of violence and abuse.**

*CRPD Civil Society* reports that police often do not regard such matters as a police matter as they assume that it will be dealt with by the service provider, even if the violence or abuse occurs within that facility. This also causes abuse and violence against people with disabilities to remain concealed, unrecognised, and considered as "different". It demonstrates the lack of awareness and skill among the community to respond appropriately to violence and abuse of people with disabilities. There is an urgent need for legislative recognition of the types of violence to assist in addressing it at the systemic level.

**Recommendation 22: Urgently amend the *Domestic Violence and Protection Orders Act 2008 (ACT)* to incorporate the NSW definition of household, which extends to people with disabilities living in various arrangements, to provide greater security for people with disabilities and enable better recognition and responses to the violence and abuse experienced by them in their homes.**

The domestic relationships of people with disabilities who live in the broader community are also not covered under the ACT legislation, including those relying on paid or unpaid carers who are not family members, or those living in other group arrangements. While assault laws might cover some of these circumstances, the protections available to assault victims are not the same as and are not adequate for those who have experienced violence in their homes, and the available responses are less robust.

While the NDIS may provide broader housing options for people with disabilities it will not overcome the acceptance of violence in their lives, the lack of recognition of violence as violence – particularly domestic violence – and the different ways that violence is experienced by people with disabilities. Nor will the NDIS address the continuing acceptance of group or congregate living environments as appropriate for people with disabilities.

The recent expansion of the Official Visitor legislation in the ACT to include people with disabilities is one small step in the right direction. However, there remains scarce funding and strategies at an adequate level to address these human rights violations for people with disabilities, which are deeply embedded and perpetuated by the current disability support system and are hidden from the wider community.

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<sup>82</sup> Murray, S., & Powell, A. (2008) *Sexual assault and adults with a disability: Enabling recognition, disclosure and a just response*. Published by the Australian Institute of Family Studies.

<sup>83</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

## **Restrictive practices – Convention on the Rights of Persons with Disabilities (CRPD) 14 and 15**

The ACT is committed to observe the following:

- 1. States Parties shall ensure that persons with disabilities, on an equal basis with others:
  - (a) Enjoy the right to liberty and security of person;
  - (b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty. (CRPD Article 14)
- 2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment. (CRPD Article 15)
- ACT Human Rights Act 2004 section 18 (2): No-one may be deprived of liberty, except on the grounds and in accordance with the procedures established by law.
- ACT Disability Services Act 1991: People with disabilities have the same right as other members of society to receive services in a manner that results in the least restriction of their rights and opportunities.

The ACT must engage in measures that prevent and eliminate the use of restrictive practices to meet its legislative and human rights obligations. Restrictive practice is defined as any intervention and/or practice used to restrict the rights or freedom of action or movement of a person with disability.<sup>84</sup> These practices are often used when a person with disability engages in behaviours that are dangerous to themselves or others. This is labelled 'challenging behaviour' or 'behaviours of concern'.<sup>85</sup> It is estimated that between 44 and 80 per cent of people with disabilities who display 'behaviours of concern' are subject to restrictive practices.<sup>86</sup>

These practices restrict a person's rights<sup>87</sup> and can have significant adverse impacts on the person's mental and physical health and wellbeing.<sup>88</sup> When restrictive practices are used a person with disability is prevented from having choice and control and can be restricted from enjoying the most basic of freedoms such as accessing food at their own liberty from the kitchen or taking a shower when they feel like it. This is unacceptable and would not be tolerated by most of the community were they aware of these practices.

Advocacy for Inclusion has observed that restrictive practices are used in various disability service settings across the ACT<sup>89</sup> including supported accommodation, respite facilities and day activity services. Advocacy for Inclusion is deeply concerned that these practices are used inappropriately in breach of the person's human rights when other supportive measures could be used instead. They can also constitute degrading and humiliating treatment and be used as a form of discipline, control, coercion and misuse of power by staff.<sup>90</sup>

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<sup>84</sup> WA Disability Services Commission. (2011). *Restrictive practice(s) issues paper*. <http://www.disability.wa.gov.au/Global/Publications/For%20disability%20service%20providers/Guidelines%20and%20policies/Behaviour%20Support/Restrictive%20Practices%20Issues%20Paper.pdf>

<sup>85</sup> Spivakovsky, C. (2012). *Restrictive Interventions in Victoria's Disability Sector Issues for Discussion and Reform*. <http://www.publicadvocate.vic.gov.au/file/Restrictive%20interventions%20discussion%20paper.pdf>

<sup>86</sup> Lowe, K., Allen, D., Brophy, S., & Moore, K. (2005). The management and treatment of challenging behaviours. *Learning Disability Review*, 10(2), 34-37

<sup>87</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

<sup>88</sup> Spivakovsky, C. (2012). *Restrictive Interventions in Victoria's Disability Sector Issues for Discussion and Reform*. <http://www.publicadvocate.vic.gov.au/file/Restrictive%20interventions%20discussion%20paper.pdf>

<sup>89</sup> See for example, Advocacy for Inclusion. (2010). *The use of chemical restraint in people with disabilities*.

[http://www.advocacyforinclusion.org/index.php?option=com\\_content&view=category&layout=blog&id=48&Itemid=59](http://www.advocacyforinclusion.org/index.php?option=com_content&view=category&layout=blog&id=48&Itemid=59)

<sup>90</sup> CRPD Civil Society. (2012). As above.

Practices occurring in ACT services include:

- Seclusion – where residents are restricted from leaving their home or are secluded in a room part of their house.<sup>91</sup>
- Chemical restraint – where people with disabilities are administered medication for the primary purpose of managing or influencing their behaviour.<sup>92</sup>
- Physical restraint – where a person uses their own body to restrict a person’s movement or behaviour.<sup>93</sup>
- Environmental restraint – involves restricting a person’s behaviour or movement by changing or controlling the person’s environment.<sup>94</sup> For example, the removal of taps, or the use of locks on cupboards and on doors to parts of the home such as the kitchen is practiced in a number of supported accommodation homes across the ACT.

Other forms of restriction include mechanical restraint, whereby devices are used to control a person’s behaviour or movements.<sup>95</sup>

Because of the serious nature of restrictive practices the *Restrictive Practices Cross-Jurisdictional Reference Group* has been developed as a national initiative to reduce and prevent the use of restrictive practices. However, actions in the ACT have not gained momentum and there are major gaps in legislation, policy and practice to monitor and prevent restrictive practices. In the absence of systemic measures to prevent and eliminate restrictive practices the ACT is failing to meet its Human Rights obligations.

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) advise that in order to reduce the use of restrictive practices organisational **cultural change** is required, including through staff training. They also recommend that chronic staff and resource shortages result in the use of restrictive practices when it would otherwise not be needed with improved supports.<sup>96</sup>

Moore and Haralambous<sup>97</sup> found that aged care workers were more likely to use restraints if they did not have adequate time or resources to respond in a less restrictive manner. Banerjee<sup>98</sup> found that aged care staff were more likely to use restraints if they had not received appropriate training to respond to the needs and behaviours of service users. Further, some people with disabilities may display ‘behaviours of concern’ to communicate their needs and preferences.<sup>99</sup> It is particularly important that they receive adequate support to communicate and exercise their choices instead of subjecting them to restrictive practices to silence them as a matter of convenience. The ACT must undertake measures to reduce and prevent the use of restrictive practices and to eliminate inappropriate use of restrictive practices.

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<sup>91</sup> WA Disability Services Commission. (2011). *Restrictive practice(s) issues paper*. <http://www.disability.wa.gov.au/Global/Publications/For%20disability%20service%20providers/Guidelines%20and%20policies/Behaviour%20Support/Restrictive%20Practices%20Issues%20Paper.pdf>

<sup>92</sup> WA Disability Services Commission. (2011). As above.

<sup>93</sup> Spivakovsky, C. (2012). *Restrictive Interventions in Victoria’s Disability Sector Issues for Discussion and Reform*. <http://www.publicadvocate.vic.gov.au/file/Restrictive%20interventions%20discussion%20paper.pdf>

<sup>94</sup> Spivakovsky, C. (2012). As above.

<sup>95</sup> Spivakovsky, C. (2012). As above.

<sup>96</sup> RANZCP. (n.d.). *Feedback about the Restrictive Practices Cross-Jurisdictional Reference Group proposed national strategy on restraint and seclusion prevention in disability services*. <http://www.ranzcp.org/Files/ranzcp-attachments/Publications/RP-SUB-RANZCP-response-FINAL-20120216-SD.aspx>

<sup>97</sup> Moore, K. and Haralambous, B. (2007). Barriers to Reducing the use of Restraints in Residential Elder Care Facilities. *Journal of Advance Nursing*, 58(6), 532-540.

<sup>98</sup> Banerjee, S. (2009). *The Use of Antipsychotic Medication for People with Dementia: Time for Action*. A Report for the Minister of State for Care Services. Department of Health, Crown UK.

<sup>99</sup> Spivakovsky, C. (2012). As above.

**Recommendation 24: Resource improved support for people with disabilities to prevent and reduce the use of restrictive practices, and eliminate inappropriate use of restrictive practices.**

**Recommendation 25: Resource the development of training and resources for disability support workers aimed at eliminating inappropriate use of restrictive practices and at eliminating and preventing the use of restrictive practices generally.**

There is minimal empirical evidence available about the use of restrictive practices in Australia to inform policy and practice in the disability sector. These data should be collected, analysed and shared across Australia to allow for national benchmarking on restrictive practices.<sup>100</sup> This is highly important as an evidence-based measure to promote quality service and monitor the use of restrictive practices used on some of the most marginalised and segregated people with disabilities. The lack of systematic data collection across Australia makes this impossible.<sup>101</sup>

Victoria developed the Restrictive Intervention Data System (RIDS), whereby all disability service providers that use restrictive practices are registered with the Office of the Senior Practitioner. Service providers use the RIDS for reporting and monitoring the use of restrictive practices. Such measures also assist in raising awareness of the issue among organisations and support workers. The ACT must undertake the same measures as Victoria in order to monitor, eliminate and prevent the use of restrictive practices, and to contribute to national data collection. The responsibility for holding and monitoring the data should be allocated to the Official Visitor as an independent statutory function.

**Recommendation 26: Develop independent statutory functions, as done in Victoria for the Official Visitor, to systematically collect and analyse data on restrictive practices across all disability service providers in the ACT to monitor the use of restrictive practices and produce information that will contribute to developing policy and practice aimed at reducing and preventing restrictive practices and eliminating their inappropriate use in the ACT and nationally.**

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<sup>100</sup> Webber, L. S., McVilly, K. R., Stevenson, E., & Chan, J. (2010). The use of restrictive interventions in Victoria, Australia: Population data for 2007–2008. *Journal of Intellectual & Developmental Disability*, 35(3), 199–206

<sup>101</sup> Webber, L. S., McVilly, K. R., Stevenson, E., & Chan, J. (2010). As above.

## **Respect for the home and family – Convention on the Rights of Persons with Disabilities (CRPD) 23**

The ACT Government has the following commitments:

- 1. *States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:*
  - (a) *The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;*
  - (b) *The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided.*
- 4. *States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents. (CRPD Article 23).*
- 1. *States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence. (Convention on the Rights of the Child [CRC] Article 9).*
- 1. *The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents. (CRC Article 7).*

The ACT Government must develop structures that promote the right of people with disabilities to found a family and raise their children. Article 23 of the CRPD, respect for the home and family, is a grossly exploited area for people with disabilities. The main reason for this is continuing paternalistic community attitudes; people with disabilities are widely perceived as asexual and child-like.<sup>102</sup> They are not often understood as having the same reproductive rights as people without disabilities. These issues expand to impact Australia's obligations as a signatory to the United Nations *Convention on the Rights of the Child*, specifically Article 7 and 9, the right for the child to be raised by their birth parents.

A large portion of Advocacy for Inclusion's consumers includes parents with disabilities, who have minimal choice and control over their own fertility and family plans. Many have had their children removed and placed into foster care. Some consumers are constantly at risk of having their children removed by child protection services and most likely would have without persistent advocacy to challenge the attitudes and assumptions about people with disabilities and their parenting rights. In Advocacy for Inclusion's experience, children are removed from their parents because the parent has a disability. There is a perception that the person cannot parent simply because of the disability. This is a misunderstanding with catastrophic outcomes for children and families.

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<sup>102</sup> Llewellyn, G., & McConnell, D. (2005). You have to prove yourself all the time: People with learning disabilities as parents. In P. G. Goward, & P. Gordon Ramcharan, *Learning disability: A life cycle approach to valuing people*. Maidenhead: McGraw-Hill Professional Publishing.

A study by Llewellyn, McConnell and Ferronato<sup>103</sup> of two Children's Courts in NSW Australia revealed that parents with cognitive disabilities were involved in almost one third of child protection cases. The study found a disproportionate amount of children of parents with intellectual disability were placed on wardship orders and outside of the family network. The researchers concluded that the overrepresentation of parents with disabilities in child protection proceedings relate to apparent discriminatory attitudes towards parents with disabilities in the court system and among child protection agencies.<sup>104</sup> Advocacy for Inclusion sees the same issues in attitude in the ACT among the community, authorities and the courts.

The information existing in Australia and internationally overwhelmingly indicates that many parents with disabilities lack appropriate support to parent,<sup>105 106 107</sup> and for some this contributed to the removal of their child from their care.

Furthermore, there is a preoccupation with the deficits of the parent's disability<sup>108</sup> and an ongoing misconception among child protection services and the court that parents with disabilities, particularly intellectual disability, are unable to improve any parenting difficulties they may experience.<sup>109 110</sup> Advocacy for Inclusion has seen cases where the parent is scrutinised for not learning at the same pace or through the same conventional methods as other people without disabilities. Sometimes child protection workers or community workers assume that this means that the person will not learn at all or will not improve.

The belief that parents with intellectual disabilities cannot or refuse to learn to parent well is based on prejudice against people with disabilities as it is not empirically evidenced and there is a significant amount of refuting empirical research.<sup>111 112 113</sup> Parents with disabilities unjustly have their children removed based on the ill-informed judgement that they cannot or refuse to learn new skills.

*If you look at the evidence in all the cases we run before the court, in 50 per cent of them [cases involving a parent with disability] there is evidence there. In 50 per cent there isn't . . . we don't have the evidence ~ Lawyer representing child protection agency.<sup>114</sup>*

Because a person's disability is long-term some people with disabilities may need support on an ongoing basis to continue parenting tasks and retain parenting skills. This is just the same for people with disabilities who need ongoing assistance caring for themselves such as personal care and domestic assistance.

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<sup>103</sup> Llewellyn, G., McConnell, D. & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample, *Child Abuse & Neglect*, 27(3), 235-251. doi: 10.1016/S0145-2134(03)00004-8

<sup>104</sup> McConnell, D., Llewellyn, G., & Ferronato, L. (2002). Disability and decision-making in Australian care proceedings. *International Journal of Law Policy and the Family*, 16(2), 270-299. doi: 10.1093/lawfam/16.2.270

<sup>105</sup> Booth, T., & Booth, W.. (2005). Parents with learning difficulties in the child protection system: Experiences and perspectives. *Journal of intellectual disabilities*, 9(2), 109-129

<sup>106</sup> Gore, N. (2010). Building effective support for learning disabled parents. *Community Care*, (1844), 34-35. Retrieved from [www.ebscohost.com](http://www.ebscohost.com)

<sup>107</sup> Starke, M. (2010). Encounters with professionals: views and experiences of mothers with intellectual disability, *Journal of Intellectual Disabilities*, 14(1), 9-19. doi: 10.1177/1744629510373052

<sup>108</sup> Lamont, A., & Bromfield, L. (2009). Parental intellectual disability and child protection: key issues. *National Child Protection Clearing House*, (31), 1-18. Retrieved from [www.aifs.gov.au/nch/pubs/issues/issues31/issues31.html](http://www.aifs.gov.au/nch/pubs/issues/issues31/issues31.html)

<sup>109</sup> McConnell, D., Llewellyn, G., & Ferronato, L. (2002). As above.

<sup>110</sup> Booth, T., & Booth, W. (2004). Findings from a court study of care proceedings involving parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1(3-4), 179-181.

<sup>111</sup> Llewellyn, G., McConnell, D., Honey, A., Mayes, R., & Russo, D. (2003). Promoting health and home safety for children of parents with intellectually disability: A randomised controlled trial, *Research in Developmental Disabilities*, 24(6), 405-431. doi: 10.1016/j.ridd.2003.06.001

<sup>112</sup> Monsen, K., Sanders, A., Yu, F., Radosevich, D., & Geppert, J. (2011). Family home visiting outcomes for mothers with and without intellectual disabilities, *Journal of Intellectual Disability Research*, 55(5), 484-499. doi: 10.1111/j.1365-2788.2011.01402.x

<sup>113</sup> Tarleton, B., & Ward, L. (2007). "Parenting with support": The views and experiences of parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4(3), 194-202. doi: 10.1111/j.1741-1130.2007.00118.x

<sup>114</sup> McConnell, D., Llewellyn, G., & Ferronato, L. (2002). As above. p. 285.

In 2012, Colleen Pearce, Public Advocate of Victoria, states:

*I am increasingly concerned that children are being removed from parents with a disability based solely on that disability, and not because the cases meet the relevant tests... Very often their child is removed not because the parent has harmed or neglected them, but because the child is seen as being at risk of neglect. The appropriate response to this is to provide support, encouragement, help and education.*<sup>115</sup>

Currently, resources are applied to the removal of children from these families – the most expensive, traumatic, and interventionist option – instead of providing guidance and support. Funding would be much more effectively and efficiently placed into support for these parents and their children as described above rather than into foster placements, which are expensive, chronically under resourced and often result in long-term adverse impacts on young people, such as homelessness.<sup>116</sup>

The ACT Government must fund supports for parents with disabilities. Lamont and Bromfield<sup>117</sup> conducted a literature review of existing research and concluded that supports for parents with disabilities should be:

- Prevention focused – services be targeted at early intervention and support parents to learn and retain parenting skills early to prevent the need for crisis intervention and the removal of children.
- Family-centred – This is instead of a child-centred approach, which is acutely focused on the child and can cause the rights of parents with disabilities to be overlooked or disregarded to the detriment of the rights of the whole family, including the child. The family must be viewed as interconnected. The child's particular vulnerability can be appreciated and given special regard through a family-centred approach that respects and promotes the needs, rights and responsibilities of each family member and the way these are interrelated.
- Long term – some people with disabilities need ongoing support to parent over the long term. Parents should be supported to become as independent as possible however the ongoing nature of disability means that some parents will need some degree of ongoing support to parent. This should not be seen as a deficit; rather it must be seen as a disability support need.
- Strengths based and partnership approach – deficits and risks based approaches can cause more harm than good<sup>118</sup>. A strengths focus is perhaps the most important aspect of an approach to supporting parents with disabilities effectively. A good way to foster resilience in children is to foster it in the parents.<sup>119</sup> Approaches should focus on supporting parents to harness and build upon their family strengths. Programs must work alongside parents rather than in a paternalistic way.
- Home based – parents with disabilities who have higher support needs require practical support in their own home. Some parents will require intensive 24 hour daily support in the home especially in the first weeks or months of their child's life, even though the parents may not usually require this level of support when they do not have an infant. Some parents may need physical support and others may need home based mentoring. Again, this must be seen as a disability support need.
- Flexible – people with disabilities are not a homogenous group of people and require services that respond to their various needs and goals.

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<sup>115</sup> Pearce, C. (15 December 2012). Disability no bar to good parenting. *The Age*. <http://www.theage.com.au/opinion/politics/disability-no-bar-to-good-parenting-20121214-2bf75.html>

<sup>116</sup> FAHCSIA. (2008). *The road home: A national approach to reducing homelessness [White Paper]*. Retrieved from [www.fahcsia.gov.au](http://www.fahcsia.gov.au)

<sup>117</sup> Lamont, A., & Bromfield, L. (2009). *Parental intellectual disability and child protection: Key issues*. National Child Protection Clearing House, (31), 1-18. [www.aifs.gov.au/nch/pubs/issues/issues31/issues31.html](http://www.aifs.gov.au/nch/pubs/issues/issues31/issues31.html)

<sup>118</sup> Connolly, M. (2010). Engaging family members in decision making in child welfare contexts. In D. Scott & F. Arney (Eds.), *Working with vulnerable families: A partnership approach*. Port Melbourne, VIC: Cambridge University Press

<sup>119</sup> Saleebey, D. (2009). *The strengths perspective in social work practice* (5<sup>th</sup> ed.). Boston: Allyn & Bacon.

Such supports are widely unavailable or non-existent in the ACT. There is clearly no genuine attempt being made to fulfil obligations under CRPD Article 23 and CRC Article 7 and 9.

***In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.***<sup>120</sup>

The ACT urgently needs parenting supports for people with disabilities to fulfil their right to be parents and have choice and control over their fertility and family plans. Advocacy for Inclusion has raised this matter since 2009 and is yet to see any budget allocations to address these serious issues.

**Recommendation 27: Advocacy for Inclusion reiterates its recommendations of 2009, 2010 and 2012 - the ACT Government must establish comprehensive and intensive parenting and family support measures for families headed by parents with disability aimed at keeping children in the care of their birth parents. Programs must:**

- include long-term and home-based supports;
- be flexible and sensitive to the needs of parents with disabilities;
- be Family-centred;
- be strengths-based; and,
- be prevention focused.

**Recommendation 28: Fund mandatory human rights based disability awareness training for Care and Protection Services workers.**

**Recommendation 29: Fund the development of peer support groups for parents with disabilities.**

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<sup>120</sup> United Nations. (2006). *Convention on the Rights of persons with Disabilities*. Article 23.4

## **Employment – Convention on the Rights of Persons with Disabilities (CRPD) 27**

- Article 27 of the CRPD states that people with disabilities have the right to access work on an equal basis with people without disabilities, including in freely chosen or accepted labour market and in an open and inclusive work place.
- The *National Disability Strategy Economic Security Areas for Future Action* commits governments to:
  - 4.1 *Improve employer awareness of the benefits of employing people with disabilities;*
  - 4.2 *Reduce barriers and disincentives for the employment of people with disabilities;*
  - 3.4 *Improve employment, recruitment and retention of people with disabilities in all levels of public sector employment and in funded organisations.*
- The ACT is committed to the vision: *I can engage in public and private sector employment in work that suits my needs and abilities. (Future Directions Strategic Priority 2)*

The ACT Government must improve inclusive employment for people with disabilities. Statistics show that people with disabilities in Australia have nowhere near equal access to employment. They have minimal choice and control over their employment and career pathways because of the major barriers and disincentives to accessing and remaining in the workplace. Almost half (45%) of people with disabilities live in or are border-lining poverty; more than 2.5 times the rate of people without disabilities.<sup>121</sup> The inaccessibility of the workplace and poor pay in the employment options that are available has a significant role in this.

While the number of people without disabilities in the workforce has been steadily rising, the number of those with disabilities has stagnated and, for some groups, declined.<sup>122</sup> Since 1993, the numbers of Australians with disabilities employed by the public sector has been dropping; from 5.8% in 1993 to 3.8% in 2003-2004.<sup>123</sup> In comparison with other countries, Australia is ranked 21 out of 29 OECD countries in employment rates for people with disabilities.<sup>124</sup>

### **Recommendation 30: The ACT to undertake sector development to improve the accessibility, accommodations and supports for employment of people with disabilities in the public sector, including the development of meaningful positions targeted at people with disabilities.**

There are many **barriers** for people with disabilities to enter and remain in the work place in the ACT:

Many employers think that a person with disability would never be the right person for a job or that there would be increased costs associated with hiring them. However, employers who have employed people with disabilities have found that they are loyal, reliable and get the job done, and they say they would employ more people with disabilities in the future.<sup>125</sup> As per the *National Disability Strategy*, the ACT Government must raise awareness amongst employers of the benefits of employing people with disabilities.

### **Recommendation 31: The ACT to develop programs aimed at raising community awareness of the benefits of employing people with disabilities.**

Young people with disabilities do not have access to adequate and collaborative programs that assist their transition from school into employment and post school options<sup>126</sup>. At the ACT Disability Advocacy Network's election forum in August 2012, which major political party spokespeople attended, numerous community members persistently identified this as a major concern. They were concerned that there is no meaningful and

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<sup>121</sup> Williams, R. (2010). *Model of Citizenship Support*. (Discussion Paper, Julia Farr Association)

<sup>122</sup> ABS. (2003). Productivity Commission, Volume 2: Appendices, pA.2. *Persons aged 15-64 years living in households*.

<sup>123</sup> Australian Human Rights Commission. (2006). *National Inquiry into Employment and Disability*.

<sup>124</sup> OECD. (2010). *Sickness, Disability and Work: Breaking the Barriers - A Synthesis of Findings across OECD Countries*.

<sup>125</sup> DEEWR. (2011). *Employer perspectives on recruiting people with disability and the role of Disability Employment Services*.

<sup>126</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

practical career advice, planning and work experience for young people with disabilities during their school years. The community has identified that it is important for these programs to begin in the early years of high school.<sup>127</sup> The ACT government must ensure adequate funding and well-coordinated career and post school options for young people with disabilities.

**Recommendation 32: Increase funding to career and post school options programs for young people with disabilities to start in the early years of high school.**

The *CRPD Civil Society Report* to the United Nations advises that the punitive aspects of the Federal Disability Employment Services (DES) program from the Commonwealth's *Social Security Act 1991* cause barriers. Since its introduction in 2010, this program has not achieved significant employment improvements. Only one in four program participants find employment and only 14% go on to sustain employment or training.<sup>128</sup> Programs must be rights-based in order to enhance their effectiveness.<sup>129</sup>

**Recommendation 33: All employment programs funded and supported by the ACT Government must be human rights-based instead of punitive.**

There are a number of **disincentives** for people with disabilities to enter and remain in the work force:

The ACT Government is applying commonwealth funding for enhanced services and NDIS readiness to sheltered workshops, now known as Australian Disability Enterprises (ADE), where people with disabilities are segregated from the rest of the community. Instead, the ACT Government should lead the way on resourcing work places to accommodate people with disabilities in mainstream employment so that they are not segregated in specialised workplaces. This includes making supported positions available for people with disabilities in mainstream employment. For example, Goodwill Engineering, an ADE, recently modified their workplace so that people with disabilities could perform a greater range of tasks.<sup>130</sup> This could be done in mainstream workplaces to make them more inclusive.

The Federal Supported Wage Systems allow employers to pay people with disabilities less than the minimum wage. Under this scheme many people with disabilities are earning only a few dollars an hour. This contradicts CRPD Article 27. *Nojin v Commonwealth of Australia* [2012] FCAFC 192 involves a case where two individuals with disabilities were paid a disturbing \$1.79 per hour.<sup>131</sup> These individuals recently won the case and the court concluded that the competency test used to determine wages for people with disabilities "unlawfully discriminated against the Applicant in contravention of s 15 of the *Disability Discrimination Act 1992*".<sup>132</sup> Advocacy for Inclusion has seen cases where people are earning a couple of dollars an hour in the ACT.

**Recommendation 34: The ACT to cease funding of segregated work places and instead apply these funds to resourcing mainstream work places to accommodate people with disabilities, including in both open and supported positions, for proper pay.**

DES providers are not funded to assist employed people with disabilities to find new jobs.<sup>133</sup> Advocacy for Inclusion has encountered this problem in the ACT. Consumers are advised that they need to quit their jobs to get job seeker assistance or try their chances in mainstream employment agencies. Mainstream employment agencies are unfortunately not designed to suit the needs of many people with disabilities. The DES system effectively forces people to stay in an unsatisfying job in order to maintain the support they need to be

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<sup>127</sup> ACT Greens. (2012). *Planning, navigation and meaningful opportunities: Post school options for young people with disability in the ACT*. [http://act.greens.org.au/sites/greens.org.au/files/DISCUSSION%20PAPER\\_Post%20School%20Options%20for%20Young%20People%20with%20Disability.pdf](http://act.greens.org.au/sites/greens.org.au/files/DISCUSSION%20PAPER_Post%20School%20Options%20for%20Young%20People%20with%20Disability.pdf)

<sup>128</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

<sup>129</sup> CRPD Civil Society. (2012). As above.

<sup>130</sup> disAbility eNews Issue 197

<sup>131</sup> See judgement at <http://www.judgments.fedcourt.gov.au/judgments/Judgments/fca/full/2012/2012fcafc0192>

<sup>132</sup> As above.

<sup>133</sup> Department of Education Employment and Workplace Relations, Deputy Secretary, personal communication, 5 June 2012.

employed. The ACT must provide people with disabilities the support they need to freely choose and accept a job as per their rights in the CRPD Article 27.

**Recommendation 35: As a member of COAG, the ACT advocate for reforms in federal employment programs to improve support for people with disabilities, including those who are already employed, to find and apply for jobs, and undertake career development and changes.**

In Australia, the lack of support and incentives for people with disabilities to enter the work force and build their career means that employment remains “a pipe dream and/or a source of difficulty and distress for many people with disabilities.”<sup>134</sup>

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<sup>134</sup> Advocacy for Inclusion Submission to ACT Budget Consultation 2012-2013

## **Access to Justice – Convention on the Rights of Persons with Disabilities (CRPD) 13**

The ACT Government has the following commitments to support people with disabilities to access justice:

- *S 8 ACT Human Rights Act 2004: Recognition and equality before the law*
  - (1) *Everyone has the right to recognition as a person before the law.*
  - (2) *Everyone has the right to enjoy his or her human rights without distinction or discrimination of any kind.*
  - (3) *Everyone is equal before the law and is entitled to the equal protection of the law without discrimination. In particular, everyone has the right to equal and effective protection against discrimination on any ground.*
- *States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. (CRPD Article 12)*
- *1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.*  
*2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff. (CRPD Article 13)*
- *National Disability Strategy 2.7: Provide greater support for people with disability with heightened vulnerabilities to participate in legal processes on an equal basis with others.*

The ACT prides itself on having the first human rights compliant prison in Australia; the ACT is in a prime position to develop all judicial systems that are human rights compliant. There are fundamental flaws within the ACT justice system that exclude and discriminate against people with disabilities. People with disabilities are overrepresented in the justice system as complainants, litigants, defendants, victims and other witnesses.<sup>135</sup> However, they experience major barriers to accessing and being heard in the court system.

Research from Monash University has revealed that 50 per cent of Australian children in juvenile detention have a communication or language disorder.<sup>136</sup> A progressive education program, Parkville College, is being introduced at Melbourne's Parkville Juvenile Detention Centre due to the success a similar model has had in the United States. Professor Pamela Snow advises that the more violent the offence, the more likely the child has speech difficulties:

*They've learnt to escalate things quickly to physical violence. But they also lack the verbal tool-kit to navigate their way through the myriad of little social interactions that we all have to manage every day.*<sup>137</sup>

Some people with communication disabilities may act violently or aggressively in order to communicate their needs in an attempt to exercise choice and control over their own lives. The program is designed to provide education that meets the needs of detainees with communication disabilities to help them be restored back into the community and prevent recidivism.

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<sup>135</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities.*

<sup>136</sup> Milligan, L. (20 February 2013). Juvenile detention program combats language disorders. *ABC News.*  
<http://www.abc.net.au/news/2013-02-20/language-school-launched-in-juvenile-detention-centre/4530572>

<sup>137</sup> Professor Pamela Snow quoted in Milligan, L. (20 February 2013). Juvenile detention program combats language disorders. *ABC News.*  
<http://www.abc.net.au/news/2013-02-20/language-school-launched-in-juvenile-detention-centre/4530572>

**Recommendation 36: The ACT to investigate the Parkville College model of education with a view to implement such a program at Bimberi Youth Justice Centre targeted at reducing recidivism and successful restoration of young people with disabilities into the community.**

A recent study by the Murdoch Children's Research Institute found that one in five children starting primary school has a speech or communication problem. Speech pathologists advise that early intervention is crucial to assist children with communication difficulties to prevent them from entering juvenile detention and a lifetime of imprisonment.<sup>138</sup> In the ACT there is a chronic shortage of speech pathologists and speech therapy programs for children and adults with disabilities. This must be targeted by the ACT government to improve the inclusion of people with disabilities in the community and to address their overrepresentation in the criminal justice system.

**Recommendation 37: The ACT to significantly increase funding for speech therapy for children and adults with disabilities with a view to improve their independence and inclusion in the community, and as part of an initiative to address the overrepresentation of people with disabilities in the criminal justice system.**

People with disabilities are widely and significantly economically disadvantaged in Australia.<sup>139</sup> This reduces their access to legal support and representation considerably and exacerbates their barriers to justice. At Advocacy for Inclusion consumers have had their cases turned down by Legal Aid as the risk that their case will not be successful is greater than other cases. This includes extremely serious matters such as appealing child protection orders. As a result many people with disabilities are unable to have their matters heard in court. Resources for legal support and representation must be improved for people with disabilities.

**Recommendation 38: The ACT must fund Community Legal Centres and Legal Advocacy to improve legal representation and support for people with disabilities.<sup>140</sup>**

The ACT Human Rights Commission has a substantially reduced capacity to address complaints due to efficiency dividend requirements. This has a major impact on people with disabilities. Many, who rely on disability services for essential life-sustaining supports for most of their lives, are unable to resolve complaints independently. This is because some are isolated or they have minimal self-advocacy skills. It is also because people with disabilities depend on these services for crucial supports and raising complaints internally can result in repercussions. Some become afraid to raise complaints for fear of potential repercussions. Human Rights Complaint mechanisms are **essential** to enable people with disabilities to raise service complaints, including those regarding services that are vital for their wellbeing. The recent cuts to funding in this area mean that people with disabilities have less capacity to give feedback about poor or inappropriate services. This is unacceptable and will be unsustainable when the NDIS is introduced, which is aimed at improving choice and control for people with disabilities. The ACT must be mindful of the resources available for Human Rights Complaint mechanisms and ensure they remain adequate for the needs of people with disabilities.

**Recommendation 39: The ACT to ensure funding is adequate for people with disabilities to undertake human rights complaints via an independent body.**

In the ACT a victim or witness with disability can be deemed not a "credible witness." When this happens, the person with disability is not allowed to give evidence in court. The case is then dropped before going to trial unless a more "credible" witness comes forward. For example, Advocacy for Inclusion is aware of cases in the ACT where a person with an intellectual disability was raped. They were deemed not a credible witness due to their intellectual disability and subsequently the cases were dropped. The alleged offenders are never sent to trial.

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<sup>138</sup> Milligan, L. (20 February 2013). Juvenile detention program combats language disorders. *ABC News*. <http://www.abc.net.au/news/2013-02-20/language-school-launched-in-juvenile-detention-centre/4530572>

<sup>139</sup> Williams, R. (2010). *Model of Citizenship Support*. (Discussion Paper, Julia Farr Association),

<sup>140</sup> CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

A high profile case in South Australia regarding the sexual abuse of children with disabilities by a bus driver highlights the ways that the system fails to acknowledge and support alternative communication methods, similar to the system in the ACT. Legislative changes are being pushed as a result in South Australia. People with disabilities are more vulnerable to violence and abuse, yet the judicial system perpetuates their vulnerability by silencing them in court. This breaches Article 13 of the CRPD, which requires States Parties to provide appropriate accommodations and supports to people with disabilities to engage in all stages of legal proceedings.

This is an urgent point of change that is crucial to the safety and wellbeing of people with disabilities, who are often in most need of the court's protection. The ACT must develop mechanisms by which people with communication and cognitive disabilities can be heard in court, and their evidence given equal weight to people without disability. This includes greater flexibility to acknowledge and value alternative communication methods such as drawings, pictures, audio recordings, gestures, and the use of advocates.

**Recommendation 40: The ACT to research and develop mechanisms through which all people with disabilities, particularly those with cognitive and communication disabilities, are supported to give evidence and be heard in court on an equal basis to people without disabilities.**

**Recommendation 41: The ACT to undertake an audit of legislation to identify and address the barriers for people with disabilities to access justice.**

For some people with disabilities legal proceedings are extremely daunting and complex. Some face barriers to understanding the progress of their case. For this reason many need support to understand and engage in the process but this is rarely offered.

Advocacy for Inclusion finds that police officers, lawyers, and court staff are unskilled in working with people with disabilities. They make assumptions that the person with disability is unable to be engaged and make a credible statement or give evidence. Lawyers will speak directly with family members instead of to the person with disability about their case. This means that people with disabilities are not being properly represented and heard. Parents with disabilities in care and protection proceedings are left in the dark about how their case is progressing and are not afforded the support they need to understand and engage in the process. Resources must be applied to ensure that people with disabilities are provided "reasonable accommodation" to engage on an equal basis with others in legal processes and court hearings.

Interpreters are recognised as a necessary support throughout legal proceedings for people who do not speak English well. Supports for people with disabilities to access justice must be provided in the same regard.

**Recommendation 42: Fund mandatory training for workers in the legal system aimed at promoting skills and understanding of how to respect the rights of people with disabilities and be sensitive to their needs at all stages of legal proceedings both inside and outside of court.**

**Recommendation 43: The ACT to provide supports for people with disabilities to access justice as a fundamental right and necessity, in the same way interpreter services are regarded for people who do not speak English well.**

## **9. Conclusion**

The ACT has a long way to go to realise its intention to support choice and control for people with disabilities. As the new framework for support and service provision, alongside human rights mechanisms, a great deal of work is still to be undertaken to ensure the ACT meets its obligations and achieves the goals set by both Government and the community.

The NDIS will provide a funding framework to facilitate greater choice and control; however, it will not result in choice and control unless the structures and attitudes among the ACT community are addressed.

Now is a critical time, leading up to the launch of the NDIS, to ensure that work is done to make choice and control real, and through this to realise the human rights of people with disabilities in the ACT.

The ACT has strong rhetoric on choice and control, and a commitment to human rights, but is still lagging in practice. Without prioritising the necessary funding commitment to achieve that practice the lives of people with disabilities will continue as they are, despite the best intentions of the community.

The voice of people with disabilities is strong and wants to be engaged as an equal partner in the community, but it needs support and training to be heard.