

# advocacy for **inclusion**

Submission to  
ACT Budget Consultation 2011-12

Advocacy for Inclusion  
December 2010

## **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

Australia has ratified the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD)<sup>1</sup>. This ground breaking document outlines the expectations placed upon States Parties who have signed the CRPD, and expects countries to use the social model of disability when implementing the convention.

The social model of disability recognises that “disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.<sup>2</sup> In other words: it is not about a specific disability diagnosis, but rather about how society creates barriers which prevent inclusion and participation. This is known as the social model of disability.

Unfortunately most of Australia’s disability policy and program development, and the provision of services to people with disabilities, still relies on lengthy assessment processes which consider a person’s condition or diagnosis rather than the barriers preventing them from participating. ACT government funding has focussed historically on medicalising disability which has resulted in many people with disabilities outside specified diagnostic areas missing out on services, other people with disabilities waiting for lengthy assessment processes to be undertaken before qualifying for services, or funding being allocated to a specific diagnostic grouping of people with disabilities to the detriment of others outside that group.

Many other people with disabilities miss out because they are not considered “disabled enough” or fall into categories which are not yet recognised despite experiencing similar barriers to other people with disabilities. A recent United Nations *Guidance Note* outlines how to ask the right questions to assess disability and the assistance level required by people with disabilities. Using this tool would improve the interface between people with disabilities and available services and supports.<sup>3</sup> It would result in a more needs based approach to the provision of services.

The *ACT Human Rights Act 2004*<sup>4</sup> recognises international instruments; including the CRPD and other treaties that Australia is party to. Many of these instruments carry an expectation of a continuing improvement in the lives of people with disabilities including inclusion in the community, access to employment and education opportunities and, fundamentally, the ability to live as other members of the community do.

The key future direction for all disability funding must be to support the independence of people with disabilities, regardless of their disability diagnosis, in line with the social model of disability and Australia’s obligations under the CRPD. Over time this will enhance the ability of people with disabilities to engage in the full range of community life, and reduce their reliance on disability specific services that are separate to the broader community.

**Recommendation 1: that the ACT frames its budget, and develops all programs and policies, using the social model of disability. This should be extended to the provision of all government funded services, including non-government agencies. A social model approach**

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<sup>1</sup> *Convention on the Rights of Persons with Disabilities* - <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Convention.aspx>

<sup>2</sup> Preamble section (e) *Convention on the Rights of Persons with Disabilities* - <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Convention.aspx>

<sup>3</sup> A Guidance Note for United Nations Country Teams and Implementing Partners – United Nations Development Group, July 2010 - <http://www.undg.org/docs/11534/Disability---Guidance-note-for-UN-Country-Teams.pdf>

<sup>4</sup> *Human Rights Act 2004* <http://www.legislation.act.gov.au/a/2004-5/default.asp>

**would see the addressing of barriers through a needs based approach, rather than focussing on diagnosis and assessment specifics.**

Additionally, and critically, the voice of people with disabilities must be supported to ensure that services and supports are built, governed, and delivered by the people who use them. There is currently a very low level of involvement by people with disabilities at all levels of service delivery, including management and governance. To redress this exclusion will require a serious commitment by government and the community to training, recognition, and support.

## **2. Summary of recommendations**

Recommendation 1: that the ACT frames its budget, and develops all programs and policies, using the social model of disability. This should be extended to the provision of all government funded services, including non-government agencies. A social model approach would see the addressing of barriers through a needs based approach, rather than focussing on diagnosis and assessment specifics.

### **Including the Voice of People with Disabilities**

Recommendation 2: that the ACT Government funds 2 FTE equivalent individual advocacy positions, to match individual advocacy funds in line with most other state and territory governments, and ensure current demand can be met.

Recommendation 3: ongoing self advocacy training and resource development is fully funded as a matter of urgency. This will target those who are currently least able to participate in making decisions about their lives.

Recommendation 4: ongoing consumer representation training and support is funded, which focuses on building individual capacity and supporting consumer representatives to undertake their work.

Recommendation 5: ongoing leadership and governance training and support is funded to ensure the continual emergence of new leaders and a broader range of disability voices participates at all levels of decision making.

Recommendation 6: that the ACT government substantially increase its commitment to systemic advocacy funding to ensure research is undertaken, and to enable consumer representatives to fulfil the demands placed upon them.

### **Supporting the Rights of People with Disabilities**

Recommendation 7: Care and Protection agencies must commence recording which parents within their system are parents with disabilities.

Recommendation 8: that specific funding is allocated to pilot a parenting support service in the ACT based on the Barkuma Community Support Service model.

Recommendation 9: that a lifelong PHAMS style service is established to support people with disabilities in all facets of their lives, including parenting, living independently, and engaging with the community.

Recommendation 10: that all Care and Protection workers attend compulsory induction training in disability awareness and the rights of people with disabilities, specifically the right to be parents.

Recommendation 11: that flexible and responsive transport support is understood to be a core need for people with disabilities and funded accordingly.

Recommendation 12: that the WAT Consortium recommendations are implemented as a matter of urgency to ensure at least one source of reliable and safe transport is available to people with disabilities in the ACT.

Recommendation 13: that funding bodies recognise transport as a specific extra cost for all projects, programs and consultations which aim to include people with disabilities.

Recommendation 14: that the recommendations made in the Advocacy for Inclusion submission to the Legislative Assembly inquiry into the needs of students with disabilities be implemented.

Recommendation 15: people with disabilities must be directly asked what form of accommodation they prefer, they must be better supported to achieve that accommodation, and they must be supported to maintain the associated services which result in stable accommodation.

Recommendation 16: that government employment policy focus on improving the transport system and providing general supports for people with disabilities so that they are able to sustain employment, rather than focussing entirely on getting people into jobs.

Recommendation 17: that employers, and workplaces, are encouraged to undertake inclusion and awareness training. All employers, organisations and agencies in receipt of ACT government funding should be required to undertake inclusion and awareness training as part of their funding obligations.

### **An Accessible Community**

Recommendation 18: community hubs must be established on arterial public transport routes, and in town centres, particularly those which house organisations that engage with people with disabilities.

### **An Inclusive Community Sector**

Recommendation 19: that the ACT government fund the development of awareness and inclusion training, based on the social model of disability, run by people with disabilities through community organisations.

Recommendation 20: that the ACT government recognise that community attitudes to people with disabilities will not progress unless there is greater understanding of the rights of people with disabilities, and to fund the development of training and resources in this area delivered by people with disabilities through community organisations.

Recommendation 21: that cultural awareness training is mandatory for all disability services staff, including improved skills in supporting cultural identity.

### 3. The voice of people with disabilities

“Inclusion of people with disabilities in our community is still far from reality. Many people with disabilities live their entire life housed, supported, and attending social events fully separate from the broader community. Our community needs to move forward from considering people with disabilities as occasional participants in the community, and recognise that the rhetoric about an inclusive community must be supported by substantial action”.<sup>5</sup>

Disability advocacy organisations provide advocacy for some of the most marginalised, isolated, and excluded people in our community. These are often people who have no real voice of their own, have little or no involvement in making day to day decisions about themselves, and who have minimal opportunities to engage in the community.

A further large cohort of people with disabilities has some level of community engagement, but no experience or skills in either self advocacy or consumer representation. With no support to develop these skills as young people they are left by the wayside. This perpetuates exclusion for people with disabilities and the world remains inaccessible to them.

The Australian Institute of Health and Welfare (AIHW) has recently outlined the rate of people with disabilities living with mental illness which is alarmingly higher than for the rest of the population.<sup>6</sup> Disability advocacy organisations are aware of the silencing of people with disabilities either through community prejudices, a lack of self advocacy ability, or isolation and fear. The connection between the silencing of people with disabilities and their rate of mental illness cannot be discounted. Urgent measures are needed to overcome it.

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<sup>5</sup> *Submission to ACT Budget Consultation 2010-11 - Advocacy for Inclusion*, September 2009

<sup>6</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: AIHW.

#### **4. Including the voice of people with disabilities**

People with disabilities are silenced not by their disability, but by a lack of support, training, and inclusion. While leadership and development programs exist for other people living with disadvantage there is no comparable ongoing support for people with disabilities to build self advocacy capacity, leadership and governance skills, or consumer representation ability. Yet many government and community processes seem to expect that confident well-spoken people with disabilities will naturally emerge to participate as required. This is not realistic, and is not expected in any other sector where the voice of consumers is respected.

There are many points along the advocacy continuum (see attachment 1) where the voice of people with disabilities can be heard. Each point requires specific supports and training, yet there is very little of either available. Ranging from individual advocacy relationships, through self advocacy, peer self advocacy support, diagnostic area support groups, consumer representation, and onto leadership and governance roles which support systemic advocacy, there are many opportunities for enhancing the capacity of people with disabilities to participate in decision making and contribute to policy and program development.

The ACT allocates most of its current resources to diagnostic area support groups, with some minimal support for systemic advocacy<sup>7</sup>, and recently some targeted support for self advocacy training through a short term project.<sup>8</sup> There is no ACT government funding for individual advocacy (where the most silenced people with disabilities are part of the continuum), no funding for consumer representative training and support, nor any leadership and governance support.

The current funding model has developed organically over time in response to pressures of the day. It does not support the implementation of the CRPD, nor does it build capacity for people with disabilities to undertake their own advocacy at any level. Neither does it provide for a long term vision to build capacity for the voice of people with disabilities to be heard in a sustainable way.

#### **Individual Advocacy**

Individual advocacy supports some of the most marginalised and vulnerable people in our community. Many people with disabilities struggle to achieve positive outcomes in accessing basic services and supports, in having their fundamental rights realised, and in working towards life goals that other community members take for granted. Individual advocacy services work to achieve these outcomes.

The ACT's 2 individual advocacy organisations are currently at capacity and turn away numerous requests for assistance each week. Those being turned away are often in urgent need of assistance, have been discriminated against, or have experienced violence, abuse or exclusion and often have no other way of resolving their circumstances.

Over time self advocacy training will reduce the need for individual advocacy support, but there will always be a need for some individual advocacy services as there will always be a cohort of people with disabilities who have communication barriers and are unable to readily articulate their needs or goals.

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<sup>7</sup> Only 2 ACT organisations receive specific funding to undertake systemic advocacy work (Advocacy for Inclusion, and People with Disabilities ACT), this has a combined total of just over \$100,000.00, all other advocacy funding is paid to diagnostic area specific support groups and supports information provision and communications through alternative formats, etc.

<sup>8</sup> ACT Health is currently funding a 2 year self advocacy training project for people with disabilities living in supported accommodation based on nutrition and wellbeing.

The ACT is one of the few Australian jurisdictions that do not match federal individual advocacy funds. This has resulted in a severe shortage of individual advocacy services. Current estimates on under met need indicate that this shortfall equates to the equivalent of 2 full time positions.<sup>9</sup>

**Recommendation 2: that the ACT Government funds 2 FTE equivalent individual advocacy positions, to match individual advocacy funds in line with most other state and territory governments, and ensure current demand can be met.**

## **Self Advocacy**

There is an urgent need to build self advocacy capacity in people with disabilities. Current demand illustrates a desire by individual people with disabilities, and organisations supporting groups of people with disabilities to access self advocacy training. Advocacy for Inclusion currently carries a waiting list from individuals and organisations, who have expressed interest in self advocacy training, which we are unable to service due to a lack of funding.

People who are self advocates have a greater engagement with the community, express a greater sense of wellbeing, and use less support services. Graduates from our self advocacy courses have fulfilled their dreams of employment, made arrangements for their own living circumstances, and reduced their total reliance on support services.

Full dependence is costly to the community, to families and carers, and most importantly to the person with disability. Any reduction in full dependence has a clear cost benefit to all stakeholders.

An ongoing self advocacy training program, which delivers training, develops appropriate resources targeted to meet various needs, and provides advanced and refresher support to graduates would cost approximately \$140,000.00 per year. This includes the logistics costs associated with providing training to people with disabilities with high support needs including transport, interpreters, and alternative format resources.

Training for people with disabilities must be fully subsidised as the participant group is almost universally fully reliant on the disability support pension and lacks the means to contribute in any way, including for transport. Most funding agencies fail to understand this and expect community organisations to develop proposals which offer training for a fee, or completely exclude transport and the cost of materials.

**Recommendation 3: ongoing self advocacy training and resource development is fully funded as a matter of urgency. This will target those who are currently least able to participate in making decisions about their lives.**

## **Consumer representation**

Successful consumer representation models exist in many places, most notably in the health and mental health sectors.

The ACT urgently requires a consumer representative training package for people with disabilities, which provides for initial training, ongoing support and advanced skills development. Additionally, organisations working in consumer representation need to develop the capacity for mentoring and peer mentoring.

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<sup>9</sup> Estimates of under met need are based on the numbers of people currently turned away from advocacy services. Refer to the Advocacy Continuum in Attachment 1.

Unfortunately there has been little support for such measures for people with disabilities over many years, and this has resulted in a disability consumer movement which is small and under resourced. Yet government and the community expect engagement on a regular and consistent basis and to a high level of expertise. Without the ability to respond people with disabilities are token appointments with limited capacity. Over several years this lack of support has resulted in people with disabilities abandoning their involvement because they lack expertise, or they burn out due to a lack of rotation through available positions and consultation processes.

Consumer representatives must have an organisation that supports them with the logistics and information they require to fulfil their obligations. Without this support they will fail to act as “representatives”, but they will also struggle to engage due to the additional physical burden of making their own arrangements. An organisation supporting representatives with logistics and the collation of the latest research, comment, and discussion papers will reduce the consumer’s work to simply being representative. For people with disabilities this support is critical to sustaining engagement.

Once again, funding models to undertake this work must fully subsidise the participants as transport and training costs remain a major barrier to inclusion.

The estimated need for consumer representative support, training and coordination is 1 FTE equivalent.

**Recommendation 4: ongoing consumer representation training and support is funded, which focuses on building individual capacity and supporting consumer representatives to undertake their work.**

### **Governance and Leadership**

Observing the advocacy continuum illustrates that some graduates of self advocacy training will become candidates for consumer representation training and opportunities. Some consumer representatives will also move on to governance and leadership positions.

Highly successful leadership development programs exist for Indigenous people and for women. There are no comparable ongoing programs for people with disabilities and no current concerted effort to build capacity.

The United Nations recently commented that it “*is concerned that women with disabilities are almost entirely absent from key leadership and decision-making positions*”;<sup>10</sup> and recommended that Australia “*adopt urgent measures to ensure that women with disabilities are better represented in decision-making and leadership positions, including through the adoption of temporary special measures such as quotas and targets*”.<sup>11</sup>

This clear message of concern and urgency cannot be addressed through current means. Rather a clear effort must be made to redress a long standing oversight.

Without people with disabilities in leadership positions across all areas of society the community will never accept their ability to undertake such responsibilities. Ensuring that people with

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<sup>10</sup> *Concluding observations of the Committee on the Elimination of Discrimination against Women - Committee on the Elimination of Discrimination against Women, Forty-sixth session, 12 – 30 July 2010.*

<http://www2.ohchr.org/english/bodies/cedaw/docs/co/CEDAW-C-AUS-CO-7.pdf>

<sup>11</sup> *ibid*

disabilities who can develop the skills required to operate at the highest levels are given support and training to do so is critical to overcoming this long standing social exclusion.

Once again, the support required to ensure people with disabilities are prepared for high level representation is not currently in place. Building this support is critical to building a sustainable capacity for people with disabilities to operate at all levels. Additionally, training, mentoring and peer support are vital to ensure people with disabilities are able to work in sometimes hostile and exclusive environments – sadly many people with disabilities working in high level situations are still subjected to bullying and harassment as they are novelties for the people around them.

Support for leadership and governance could be supported by the same 1 FTE for consumer representation as these are related mechanisms. This work also needs to be fully subsidised in recognition of the high costs of working with people with disabilities.

**Recommendation 5: ongoing leadership and governance training and support is funded to ensure the continual emergence of new leaders and a broader range of disability voices participates at all levels of decision making.**

### **Systemic Advocacy**

The voice of people with disabilities must be heard across the full range of activities and issues that people with disabilities wish to engage in. It is only relatively recently that this voice has been considered at all and the infrastructure to support it is yet to be fully developed. Fortunately the enthusiasm of the government and community to hear this voice has not waned and the demand for people with disabilities to engage in consultation, program development, and service analysis has been high.

Unfortunately this demand also places significant pressure on individuals with disabilities to become experts, contribute submissions and comment without adequate resources or research capacity, and to self fund to participate. This is unsustainable and relies on the good will and capacity of a very small number of people, many of whom struggle to afford participation. Some people endanger their health by continuing to participate when they need down time for recovery but have no one to hand over to.

The ACT Government does support some community based systemic advocacy for people with disabilities, but this barely covers the ability to prepare a few submissions and attend one or two consultation processes each year. There is still a major shortfall in the ability of people with disabilities to advocate systemically, undertake research, develop resources for consumer representatives, respond to community awareness initiatives, and progress critical issues.

To be effective the ACT disability community needs to build its research and policy capacity. With current demand levels, and recognising the national program and policy development work expected over the next decade, this could be achieved with the addition of 2 FTE equivalent policy and research officers. Disability is a major area of change and development for both government and the community – responding will require a sustained capacity building effort.

**Recommendation 6: that the ACT government substantially increase its commitment to systemic advocacy funding to ensure research is undertaken, and to enable consumer representatives to fulfil the demands placed upon them.**

None of these recommendations carries a small commitment, and all need to be ongoing. These recommendations have been developed by the ACT Disability Advocacy Network in response to known gaps in capacity, and with an understanding of the demands currently being placed upon people with disabilities in the ACT. They are also in line with the expectations of the CRPD and the social model of disability.

## 5. Supporting the Rights of People with Disabilities

To support people with disabilities by working within the social model of disability, we must look at the barriers facing people and assess their individual needs to overcome those barriers. There are many barriers currently presented to people with disabilities across a range of services, including parenting support, transport, schools/education, accommodation and employment. People with disabilities have the right to engage in their community and to be supported to do so, including engaging in cultural activities.

The current support service system becomes accessible when people are in crisis and often not before that point. This means that many people with disabilities with medium level support needs miss out.

### Parenting

Historically people with disabilities were denied the right to be parents, through forced sterilisation, removal of children, and denial of relationships. “Women with disabilities have traditionally been discouraged or denied the opportunity, to bear and raise children. They have been, and continue to be perceived as asexual, dependent, recipients of care rather than care-givers, and generally incapable of looking after children.”<sup>12</sup>

People with disabilities struggle to be seen as family participants and are over represented in care and protection systems nationally. Additionally, there is low statistical collection by care and protection agencies on the presence of parents with disabilities on their books. This enhances the difficulties disability advocacy organisations face in addressing this fundamental rights shortfall, as we simply do not know exactly how big the problem is.

### **Recommendation 7: Care and Protection agencies must commence recording which parents within their system are parents with disabilities.**

The CRPD clearly states that disability should not be an impediment to parenting or founding a family: “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>13</sup> Yet, many parents with disabilities have their children placed in out of home care due to the “risk” presented by their disability. It has become clear to disability advocacy organisations that the lack of long term parenting support services contributes substantially to this situation.

If a person with disability needs personal care support it is understood that this will be life long, but when a person with disability needs parenting support there is a lack of understanding about the long term nature of that support.

In 2009 Advocacy for Inclusion recommended: **“that specific funding is allocated to pilot a parenting support service in the ACT based on the Barkuma Community Support Service model”**.<sup>14</sup> We reiterate that recommendation as a matter of urgency. There are no long term (whole of life) support services for parents with disabilities in the ACT. At best there are short term supports centred on the birth of a child, or specific short term supports later related to the parent’s disability rather than their role as a parent. There is an urgent need for a service similar to the

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<sup>12</sup> Parenting Issues for Women with Disabilities in Australia’ A Policy Paper by Women With Disabilities Australia (WWDA) May 2009

<sup>13</sup> Article 23 – Respect for home and the family, *Convention on the Rights of Persons with Disabilities* - <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Convention.aspx>

<sup>14</sup> *Submission to ACT Budget Consultation 2010-11* - Advocacy for Inclusion, September 2009

Personal Helpers and Mentors program (PHAMS), but which acknowledges the lifelong nature of disability and does not carry time limits.

**Recommendation 8: that specific funding is allocated to pilot a parenting support service in the ACT based on the Barkuma Community Support Service model.**

**Recommendation 9: that a lifelong PHAMS style service is established to support people with disabilities in all facets of their lives, including parenting, living independently, and engaging with the community.**

Additionally, it has become clear that compulsory disability awareness training would benefit all care and protection workers as part of their induction training package. In our experience Care and Protection workers have struggled with understanding how disability is a factor in some of their cases and specific training in disability awareness and the rights of people with disabilities would contribute to overcoming this.

Working with people with disabilities through a rights based approach is historically very recent and many workers across a range of agencies and services need support now in understanding how to do this.

**Recommendation 10: that all Care and Protection workers attend compulsory induction training in disability awareness and the rights of people with disabilities, specifically the right to be parents.**

## **Transport**

Transport is possibly the biggest single barrier to people with disabilities engaging with the Canberra community. Many people with disabilities live in isolation and poverty due to an almost complete incapacity to reliably leave their homes. For many transport is only available for medical appointments or specific planned activities.

The public transport system remains unusable until it is fully accessible, and taxis offer no reliable alternative.<sup>15</sup> Until transport becomes inclusive and reliable there is no real possibility for people with disabilities to work, seek an education, undertake volunteering opportunities, or participate in social and cultural events. People with disabilities are particularly excluded from spontaneous socialising and this reduces many people to outsiders as it makes it almost impossible to create and sustain relationships. This continuing exclusion also means the broader community has little experience of disability and continues to feel awkward and uncomfortable when around people with disabilities.

Recently anecdotal evidence has emerged about moves to reduce the transport support carried out by various community organisations and Disability ACT. This is totally unacceptable and does nothing to overcome the broader exclusion many people with disabilities experience. This is one area where increased funding and services are essential, rather than any diminution of currently available levels of service. Without flexible and responsive transport support other programs and services for people with disabilities become redundant.

**Recommendation 11: that flexible and responsive transport support is understood to be a core need for people with disabilities and funded accordingly.**

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<sup>15</sup> *Response to the Taxi Industry Discussion Paper* - Wheelchair Accessible Taxi Consortium, May 2010

In 2010 the Wheelchair Accessible Taxi (WAT) Consortium made recommendations about how to address the dysfunctional nature of the WAT service in the ACT. These services form the core transport response for many people with disabilities, yet they remain unreliable, unsafe in some circumstances, and expensive.

The WAT Consortium specifically recommended:

- “the operation of a not for profit WAT service run by ACTION, which integrates with overall sustainable transport planning in the ACT.
- The phasing out of existing taxi network WAT licences as they expire within the next four years, and a transition to the ACTION WAT network.
- An ability for passengers to use ACTION bus tickets as fares OR a simple swipe card system without the need for Taxi Subsidy Scheme (TSS) vouchers.
- Salaried drivers to work as part of the ACTION WAT team, with the career path opportunities that this provides.”<sup>16</sup>

**Recommendation 12: that the WAT Consortium recommendations are implemented as a matter of urgency to ensure at least one source of reliable and safe transport is available to people with disabilities in the ACT.**

A further barrier to people with disabilities participating in community life is the lack of awareness by funding agencies of the need to fund transport as part of projects undertaken by community organisations. Most people with disabilities who work with community organisations, participate in their consultations, or undertake their training, live on the disability support pension and have few resources.

Without specific transport funds within each project, which targets people with disabilities as a consumer group, there is little capacity for people with disabilities to participate. An acceptance by funding agencies of the importance of this cost to the success of projects/programs is vital.

These costs must also be factored in to all government consultations and community engagement processes without reservation.

**Recommendation 13: that funding bodies recognise transport as a specific extra cost for all projects, programs and consultations which aim to include people with disabilities.**

## **Schools/education**

The CRPD makes it clear that people with disabilities in Australia are entitled to a fully inclusive education system and equitable lifelong learning opportunities.<sup>17</sup> Despite the CRPD, and a raft of other policies and legislation regarding inclusive education, people with disabilities in the ACT continue to face barriers that prevent them from receiving an equitable education experience at all levels of the system.

Advocacy for Inclusion undertook consultations in late 2009 to ascertain the attitudes, experiences and ideas of students with disabilities, family members and education workers. The consultation process revealed a disconcerting degree of unmet need among students with disabilities in the ACT. It also highlighted a number of requirements for an education system to progress towards meeting the needs and rights of students with disabilities in the ACT.

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<sup>16</sup> *ibid*

<sup>17</sup> Article 24, *Convention on the Rights of Persons with Disabilities* - <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Convention.aspx>

Following this consultation Advocacy for Inclusion made a submission to the ACT Legislative Assembly inquiry into the needs of students with disability.<sup>18</sup> That submission made several key recommendations about the needs of students with disabilities across the education spectrum. These recommendations were:

Recommendation 1: Education providers implement person-centred measures and universal design of all education programs.

Recommendation 2: Special schools are phased out in favour of all schools providing universal inclusive programs.

Recommendation 3: A case-management team responsible for supporting each student with disability to plan and coordinate school-related supports and annual transitions throughout early childhood to viable post-school pathways in collaboration with family members, education workers and relevant services.

Recommendation 4: DET to immediately and effectively implement the ACT Government *Policy Framework for Children and Young People with a Disability and their Families*.

Recommendation 5: Education funding models need to be diversified and funding increased in a manner sufficient to support education providers to fully address the needs and rights of all students with additional learning needs, including those considered as having mild to moderate levels of need.

Recommendation 6: DET, adult learning providers and teaching courses ensure training is provided for all education workers in inclusive education philosophy and delivery.

Recommendation 7: The current category-based ACT Student Disability criteria are replaced with a system that acknowledges every student who has special learning needs.

Recommendation 8: ACT Government must deliver post-school pathways funding packages to a larger proportion of school-leavers with disabilities.

Recommendation 9: Additional financial support for adults with disabilities is needed so that completing post-secondary studies does not incur additional economic disadvantage.

Recommendation 10: Ongoing awareness campaigns about the inherent value of people with disabilities and their entitlement to receive an inclusive education are needed.

Recommendation 11: Increased transparent monitoring of schools' adherence to disability standards for education, Individual Learning Plans and funding usage.

Recommendation 12: ACT education providers be required to report on their progress towards meeting the obligations under Article 24 of the *UN Convention on the Rights of Persons with Disabilities*.<sup>19</sup>

These recommendations cover the broad range of education experiences of people with disabilities in the ACT and illustrate the pressure points on the system, the need for greater inclusion support, and a need to commit to specific outcomes for students. There remains a great deal to do to

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<sup>18</sup> <http://www.parliament.act.gov.au/downloads/submissions/12%20Advocacy%20for%20Inclusion.pdf>

<sup>19</sup> Ibid, page 5

ensure that students with disabilities receive a quality education, on an equal basis to their peers without disabilities, which serves as a path to employment and other opportunities.

**Recommendation 14: that the recommendations made in the Advocacy for Inclusion submission to the Legislative Assembly inquiry into the needs of students with disabilities be implemented.**

## **Accommodation**

The ACT Government vision and values statement for people with disabilities states: “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>20</sup> Many people with disabilities remain in group homes, struggle to find adequate support to live independently, are forced to stay with their parents, or accept inappropriate public housing options through a lack of any real choice.

While it must be recognised that cost is a factor, the experience of disability advocacy organisations is that people with disabilities are not asked what their preferred accommodation option is. This oversight leads to assumptions being made, or funding options remaining unexplored.

The CRPD states:

*“States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*

*(a) 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;*

*(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*

*(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”<sup>21</sup>*

Safe and secure housing is fundamental to the stability required to maintain other reliable services. Achieving stable, sustainable supports and services is very difficult for people with disabilities. Many live with short periods of stability between longer periods of difficulty as they work to coordinate or afford services. Without safe and secure housing it is impossible to coordinate services, gain employment, undertake an education, develop social networks, or stabilise a disability.

People with disabilities are also limited in their housing options by a lack of individual funding support. Disability advocacy organisations have noted several cases where suitable accommodation is found but cannot be pursued as the person is not attached to any specific funding that they can contribute. This applies mainly to supported accommodation options and

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<sup>20</sup> [http://www.dhcs.act.gov.au/disability\\_act/vision\\_and\\_values](http://www.dhcs.act.gov.au/disability_act/vision_and_values)

<sup>21</sup> CRPD Article 19 Living independently and being included in the community - <http://www2.ohchr.org/english/law/disabilities-convention.htm>

needs to be addressed to ensure choice becomes a reality. To find appropriate accommodation within the limited ACT market and then be denied it is distressing.

**Recommendation 15: people with disabilities must be directly asked what form of accommodation they prefer, they must be better supported to achieve that accommodation, and they must be supported to maintain the associated services which result in stable accommodation.**

## **Employment**

Employment remains an elusive goal for many people with disabilities. While some steps are being taken to address this through various Federal and ACT government programs, there is still a lack of recognition that without adequate supports and services a job is not a viable option.

Employment programs will not succeed until support, transport, and education services are accessible to people with disabilities. There is little point in wielding a large stick to “encourage” people off the disability support pension when they will be unable to sustain any job, or cannot afford to lose their pension entitlements. Governments must focus on the support and inclusion side of the equation and people will consequently pursue employment as and when they can.

Additionally, large numbers of people with disabilities gain employment only to experience workplace exclusion, harassment or bullying. Without adequate training in inclusive workplaces employers and workplaces will continue to struggle to sustain their disability workforce.

**Recommendation 16: that government employment policy focus on improving the transport system and providing general supports for people with disabilities so that they are able to sustain employment, rather than focussing entirely on getting people into jobs.**

**Recommendation 17: that employers, and workplaces, are encouraged to undertake inclusion and awareness training. All employers, organisations and agencies in receipt of ACT government funding should be required to undertake inclusion and awareness training as part of their funding obligations.**

## 6. An Accessible Community

The ACT community continues to present barriers which exclude people with disabilities. Some of these barriers are old and will take time to address; however, some are new barriers which have arisen through poorly thought out planning processes.

“An inclusive community will encompass services across the broad spectrum of life to include all services, accommodation, roads (adequate parking), schools, transport (including school transport), recreation etc. It will allow people with disabilities to engage in employment, education, and social events. By focussing on an inclusive community the reliance on a parallel world of specialist service providers will reduce. If people have friends and colleagues they are more likely to have natural supports within their community rather than being isolated and only ever having contact with paid support workers.”<sup>22</sup>

The new network of community hubs being developed for the ACT community sector will unfortunately perpetuate the exclusion of people with disabilities. Most of the hubs are located in suburban areas away from major public transport routes. Most are on hourly suburban bus routes.

Many people with disabilities test their employment readiness through volunteering with community sector organisations. Many others undertake part time employment in community sector organisations. Moving community sector organisations to areas which are poorly serviced by public transport effectively denies many people with disabilities the capacity to engage with the community sector as people with disabilities are heavily reliant on public transport.

Additionally, the capacity of community organisations to consult with people with disabilities will become more difficult as centrally located accessible venues are lost.

The ability of people with disabilities to travel independently is a core principle to supporting independence. While there are some people who are unable to travel independently there are many others who would be able to do so if accessible transport and better planning was in place.

**Recommendation 18: community hubs must be established on arterial public transport routes, and in town centres, particularly those which house organisations that engage with people with disabilities.**

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<sup>22</sup> *Submission to ACT Budget Consultation 2010-11 - Advocacy for Inclusion, September 2009*

## 7. An inclusive community sector

Disability is one of the most siloed areas of service provision in the community sector. While many other parts of the community sector have mainstreamed their work across all services and organisations, disability has been left behind. This means that people with disabilities continue to be surrounded by those concerned only with disability matters, including other consumers, and that workers in the sector are similarly isolated in understanding current good practice and what is happening in the broader community sector.

Consequently, many mainstream organisations struggle to support people with disabilities and prefer to refer them to a specialist disability organisation.

This situation is exacerbated by a lack of awareness and inclusion training appropriate to different sub-sectors, and no real understanding of the rights of people with disabilities. Funding is urgently required to develop awareness and inclusion training for women's services, alcohol and drug services, and mental health services, for example.

Several service areas have identified their need for training but without a capacity to develop that training nothing can be achieved. Specific attempts to follow through on the recommendations of the *Women with Disabilities Accessing Crisis Services*<sup>23</sup> report have so far been unsuccessful with the very real danger that the interest and momentum gained through this project will be lost.

Disability ACT has identified the need for awareness training,<sup>24</sup> but is yet to support the development or delivery of such training. The earlier iteration of *Future Directions*<sup>25</sup> clearly outlined that this work should be undertaken by community providers and people with disabilities. At present the only awareness training in the ACT is being delivered by Disability ACT by people without disabilities. It is concerning that government agencies are hindering the capacity of community providers and people with disabilities to develop income generating skills and packages by directly competing and creating an uneven playing field.

Further there is a real need for training to be developed about the rights of people with disabilities, for delivery to the broader community and to people with disabilities themselves. Current awareness training focuses almost entirely on the medicalisation of disability and the "behaviours" associated with specific types of disabilities. This is not in alignment with CRPD expectations and reinforces disability stereotypes and misunderstandings. It also reduces the capacity of training participants to work across the disability spectrum as it limits them to specialisation. While specialisation is useful in all fields of endeavour it should not be seen as a replacement for broad understanding and awareness of disability or the rights of people with disabilities.

Community attitudes towards people with disabilities still act as a major exclusionary barrier. While increasing the presence of people with disabilities in the community will assist in overcoming this over time, the community needs more immediate assistance to become more understanding of people with disabilities and their rights.

Community organisations and their workforce also need support to overcome entrenched community attitudes and exclusionary behaviour. Without a greater understanding of inclusive practices mainstream services will continue to refer people with disabilities to specialist disability

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<sup>23</sup> *Women with Disabilities Accessing Crisis Services* – Women's Centre for Health Matters, Domestic Violence Crisis Service, Women With Disabilities ACT 2009.

<sup>24</sup> *Future Directions – Towards Challenge 2014*, ACT Government Disability ACT 2009.

<sup>25</sup> Objective 1.1 *Future Directions, A framework for the ACT 2004-2008*, DHCS Disability ACT 2004.

services. While specialist services might be good at disability matters, they do not have expertise in other areas of life such as drug or alcohol dependency, housing, arts, or mental health. It is vital that services across the community sector are skilled in working with people with disabilities and are supported to become so.

All training developed and delivered to people with disabilities must be fully funded as the participants are usually some of the most isolated and disadvantaged members of our community. They are almost universally reliant on the disability support pension, and have little or no means to cover the costs of training or transport.

Training developed for community organisations and for the broader community requires development support, but can subsequently be delivered on a fee for service basis.

**Recommendation 19: that the ACT government fund the development of awareness and inclusion training, based on the social model of disability, run by people with disabilities through community organisations.**

**Recommendation 20: that the ACT government recognise that community attitudes to people with disabilities will not progress unless there is greater understanding of the rights of people with disabilities, and to fund the development of training and resources in this area delivered by people with disabilities through community organisations.**

The community sector continues to be highly collaborative in its approach to supporting Canberra's most disadvantaged community members; however, this must be recognised and supported if people with disabilities are to be supported right across the range of organisations and services available.

There are currently numerous networks and forums that bring together different groups of organisations. Unfortunately most are based on specific funding programs, and this perpetuates the siloing of expertise and workforce. Cross sector collaborative frameworks are needed to ensure a broad understanding of developments and to develop inclusive frameworks. Ideally this should be undertaken by peak bodies, working in collaboration with specialist groups like the ACT Disability Advocacy Network,<sup>26</sup> as they are best placed to work across sectors and to bring organisations with common challenges together to address specific issues like disability.

Finally, disability services struggle to support people and families from diverse cultural backgrounds and Indigenous communities. Many families, for whom English is a second language, miss out on services through a lack of understanding of processes, or through a misunderstanding of expectations. It is quite clear that those who speak loudest are more likely to access greater support. Disability services and staff need a greater understanding of cultural diversity and training in cultural awareness to reduce the risk of people falling through gaps.

**Recommendation 21: that cultural awareness training is mandatory for all disability services staff, including improved skills in supporting cultural identity.**

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<sup>26</sup> The ACT Disability Advocacy Network is a coalition of disability advocacy organisations and consumer representative organisations.

## **8. Conclusion**

This is a challenging time for disability funding and policy as work is targeted, both locally and nationally, at implementing the *Convention on the Rights of Persons with Disabilities*. Developing programs and policies which support the social model of disability, ensuring that the rights of people with disabilities are fulfilled, and that the community becomes more inclusive and comfortable with people with disabilities will not be easy.

The community sector, specifically disability advocacy organisations, is well placed to carry this work forward given adequate support. For a relatively small cost the voice of people with disabilities can be supported to be heard and developed in a sustainable way. While this work is coming from a low base due to a complete lack of support over many years, there is real capacity to change this quickly and move forward.

9. ATTACHMENT 1

ADVOCACY CONTINUUM

