

# Response to Department of Social Services Discussion Paper: Review of the National Disability Advocacy Program June 2016

# **Endorsed by Australian Federation of Disability Organisations**



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# About Disability Advocacy Network Australia (DANA) Ltd

Disability Advocacy Network Australia (DANA) is the national peak body for disability advocacy organisations across Australia. Our goal is to advance the rights and interests of people with disability by supporting advocacy organisations in their targeted advocacy as well as engaging in systemic advocacy on a national level to further these objectives. DANA works to a vision of a nation that includes and values persons with disabilities and respects human rights for all.

Our membership is comprised of advocacy organisations that work to protect the rights and interests of some of the most disadvantaged and marginalised people with disability.

# About independent disability advocacy

Independent advocacy agencies address the advocacy needs of those people with disability who are more likely to be vulnerable to abuse, neglect and breaches of their fundamental human rights. They do this through a variety of delivery models that include systemic, legal, family and individual advocacy support by paid advocates, citizen advocacy using community advocates, self advocacy development and support. (See Appendix A for description of the models).

To manage within restricted funding environments, advocacy services prioritise clients with cognitive impairments, communication barriers, complex needs, those with experience of institutionalisation, abuse or neglect, and those without strong networks of support from peers, family or friends.

Independent disability advocacy is vital to protecting and advancing the rights and interests of Australians with disabilities and contributing to the ongoing quality assurance and improvement of service systems. Independent advocacy plays a crucial role in the safeguarding of people with disability and, as such, should be funded commensurate with the critical role it performs.

People who access independent advocacy supports are among the most disadvantaged and vulnerable people with disability, and access to independent advocacy is critical to protecting and advancing their human rights. They are often experiencing multiple human rights violations, stark discrimination, and severe social exclusion and marginalisation.

# **Key Recommendations**

- The Australian government and State & Territory governments commit additional funding for the provision of independent advocacy. This is urgently required to provide sufficient supply of independent advocacy and to ensure that further gaps in advocacy provision do not develop while the NDIS rolls out in all states and territories.
- The Australian government commits recurrent funding for DANA as the national
  peak body for independent advocacy organisations. The government funds a
  national representative organisation for disability service providers recognising that
  the voice of the industry needs to be heard and to have a place in policy
  development. Equally, the legitimate, collective voice of the independent advocacy
  organisations requires ongoing funding that acknowledges the value of this specific,
  detailed, and wide-ranging perspective.
- DSS funds DANA sufficiently to build and develop capacity within independent advocacy organisations, disseminate information, run advocacy-related conferences and events, collaborate in research, provide human rights-based analysis relevant to disability issues, participate in consultations & raise awareness of the value of independent advocacy.
- DSS funds DANA to undertake targeted work on current and future workforce needs
  of independent advocacy organisations, including the profile of current advocates
  and attracting, recruiting, qualifications, training, professional development and
  support needs of the current and future advocacy workforce.
- DSS undertakes detailed consultation with the advocacy sector in the development
  of any new funding formula for distribution of funding within the NDAP, to allow
  opportunity for specific contributions arising from the experience of the
  organisations. In particular about any weightings that may be developed to address
  additional barriers, such as remoteness, language and cultural background,
  Aboriginality, and institutionalisation.
- DSS works with the advocacy sector to plan for relevant data collection and use, with
  a focus on evaluating outcomes of advocacy for the person. Organisations need to
  know in advance what pieces of information are required, and be able to plan to
  build it into their systems.
- DSS and the NDIA jointly undertake work to resolve the issues that require clarification about how decision support and safeguard supports will be practised, funded and allocated within the NDIS. That DANA and the independent advocacy

sector are active participants in this work, which would include monitoring and evaluating outcomes for consumers of those advocacy organisations that register as providers under NDIS to deliver support coordination or similar functions, under advocacy principles.

- The development of policy about decision supports recognises that independent advocates have a long history of providing decision support as an integral part of advocacy and this experience must inform the development and practise of this important policy area.
- The guidelines and policy about decision support within the NDIS be developed to be coherent with the decision-making principles articulated by the Australian Law Reform Commission -
  - 1. Every adult has the right to make decisions that affect their life and to have those decisions respected.
  - 2. Persons who may require support in decision-making must be provided with the support necessary for them to make, communicate and participate in decisions that affect their lives.
  - 3. The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives
  - 4. Decisions, arrangements and interventions for persons who may require decision-making support must respect their human rights.
- Funding for Human Rights education be made available nationally for advocacy organisations.
- Any changes to the NDAP are coherent with the National Disability Advocacy
  Framework, Quality & Safeguarding Framework and the Information, Linkages &
  Capacity Building Policy for the NDIS, so that any proposed changes in the delivery of
  independent advocacy and advocacy-type activities happens with adequate time for
  transition, if necessary, by organisations to different structures, program
  requirements, reporting requirements etc.
- DSS not proceed with any major changes to the NDAP until the Frameworks have all been finalised and the implications for independent advocacy understood clearly.
- Further consultation for this Review of NDAP needs to include direct focus groups
  with people with disability, organised with and through their representative
  organisations and DPOs. Also specifically with members of Self Advocacy Groups,
  using Easy English consultation questions and structured to allow appropriate
  support and enough time for good input.

- Any proposed restructure of the NDAP ensures as far as possible that choice of advocacy provider is available, in the same way that the NDIS provides choice to participants.
- Arising from this Review , if the selection process DSS decides to use to determine
  the next funding round for NDAP is a Tender process; DANA recommends a select
  tender for existing advocacy organisations with deliberate exclusion of organisations
  that provide traditional disability services, such as accommodation support or
  community access.
- Any such selection process should be open to applications from state and territory funded advocacy organisations, many of whom have equally as long a history of providing independent advocacy as the NDAP organisations.
- DSS take note of the current Productivity Commission inquiry into competition in human services, particularly:
   2 (b) (iii) the factors affecting consumer use of services and preferences for different models of service delivery, noting the particular challenges facing consumers with complex and chronic needs and/or reduced capacity to make informed choices
- The Australian Government acts on the recommendations of the Australian Human Rights Commission, the Australian Law Reform Commission, and the Productivity Commission, and on the intentions of its National Disability Strategy, to reduce the significant barriers preventing people with disability from accessing justice.
- Any alteration to the current arrangements for legal advocacy must be informed by recognition of
  - the major gaps existing in advocacy supports available to people with disability interacting with justice systems
  - the current efforts of independent disability advocacy organisations to educate people with disability, justice professionals and the wider community about legal rights and issues relevant to disability (on limited funding);
  - the holistic problem-solving approach taken by the independent disability advocacy sector in addressing people's legal and non-legal problems;
  - the importance of specialist support to aid effective communication between people with disability and justice professionals;
  - the valuable connection between legal advocacy and systemic advocacy, which aims to change the systems that impact on the legal rights of people with disability; and
  - the need for further consultation with the sector.

DANA welcomes further opportunities that will be provided as part of this Review, to participate with the advocacy organisations in the planned targeted workshops, and to help develop practical improvements to strengthen the advocacy sector in Australia.

# Disability Advocacy in Australia in 2016

There are currently 58 organisations funded to provide independent advocacy through NDAP (down from 76 in 1999). This equates to a **24% drop in provider options** for people with disability over the intervening 17 years.

The advocacy sector is stretched to its limits. Advocacy organisations are predominantly small organisations, whose core business is independent advocacy. As costs have increased, the capacity of independent advocacy organisations to provide advocacy has come under increasing pressure. There has been almost no change to funding amounts over the last 10 years other than partial contributions towards the cost of Quality Audits.

Further contributing to the stressful circumstances independent advocacy organisations find themselves in:

- The current **short-term funding environment** of NDAP makes it extremely difficult for organisations to plan for the medium or long-term. The 2015-16 funding agreement is a 12-month extension of the previous contracts, and the 2016-17 year agreements are also 12 month extensions, to end of June 2017.
- The National Disability Advocacy Framework (NDAF), reviewed in 2015, has not yet been agreed to and released by the Council of Australian Governments (COAG) Disability Reform Council (DRC). Responding to a review of NDAP without knowing what the revised framework that guides the program looks like is akin to trying to do a jigsaw puzzle without having the picture on the box.
- Most State and Territory governments plan to stop funding disability advocacy
  once the transition to NDIS full scheme has finished. Governments have funded
  independent disability advocacy for the past 30 years (SA ceased funding disability
  advocacy 8 years ago) and will be re-directing that funding to the NDIS. State
  governments have been directing the advocacy organisations to look to the
  Commonwealth government for future funding, or to the ILC part of the NDIS.
- The Commissioning Framework for the Information, Linkages and Capacity-Building (ILC) component of the NDIS has not been finalised. Independent advocacy organisations have been heavily involved in the consultations about the ILC and there has been an assumption that some activities that independent advocacy organisations do (e.g. education on rights, provision of independent information, some self advocacy group support, and other activities), may fit under ILC funding. Indications are that the ILC funding will be heavily oversubscribed as many community organisations will seek this funding to meet the demands in their communities and that the funding will mainly be fairly small, project-based grants. It will be impossible for organisations to continue to provide quality independent advocacy if they can only access project funding rather than recurrent funding.
- The Quality and Safeguarding Framework for the NDIS has not yet been finalised.
   Independent advocacy is a critical part of the safeguarding of vulnerable people with disability and independent advocates act as a bridge between people who have significant problems and the complaints mechanisms and legal processes that they need to use to have those issues resolved.

The Consultation Report of the Quality and Safeguarding Framework (December 2015) in Section 3.2.2 talks about advocacy under the heading of 'Someone in my corner':

"Many stakeholders (including people with disability and their families, as well as advocates) said that while family members will often play an important role in supporting people with disability, independent advocacy services and peer support networks also have important functions. These services were identified as particularly, but not only, important to people with few natural supports and people with cognitive disability. In the workshops, people with disability talked about the need for 'someone in my corner' who is independent of the NDIA and of providers....

The consultation also identified an important role for self-advocacy supports to empower people to make choices and advocate for their rights, and for systemic advocacy to identify trends and issues at the system level. What advocacy supports look like in the NDIS environment will be informed by the current review of the National Disability Advocacy Framework.

This points to an issue that DANA and the independent advocacy organisations are very aware of, that all of these Frameworks are interlinked.

DANA recommends that DSS not proceed with any major changes to the NDAP until the Frameworks have all been finalised and the implications understood clearly.

The Productivity Commission has commenced a public inquiry to examine the application of competition and user choice to services within the human services sector and develop policy options to improve outcomes.

DANA recommends that DSS take note of the Productivity Commission inquiry particularly:

2 (b) (iii) the factors affecting consumer use of services and preferences for different models of service delivery, noting the particular challenges facing consumers with complex and chronic needs and/or reduced capacity to make informed choices.

In the past year many reports have emphasised the vital role of independent disability advocacy:

- The Joint Standing Committee on the NDIS
- The Senate Inquiry into Abuse and Neglect of people with disability
- The Senate Inquiry into young people in residential aged care
- The Victorian Ombudsman: Reporting and Investigation of allegations of abuse in the disability sector
- The Victorian Parliamentary Inquiry into Abuse

These reports all affirmed the work of disability advocates but this is not enough. There needs to be a strategically planned investment of significant additional funding for independent disability advocacy. State and Territory governments need to continue to fund independent advocacy. The majority of the systems that people with disability require

advocacy to deal with are state-based systems; Health, Education, Justice, Housing, Child Protection, Transport etc. It is entirely appropriate that the jurisdictions should fund independent advocacy to assist their state residents with problems arising from the systems they provide.

However the primary funder of a national independent advocacy program will continue to be DSS via NDAP.

# Advocacy and the NDIS

Independent advocacy organisations, whose job it is to help people with disability navigate systems, have had no additional funding to assist people as the NDIS transforms the disability sector. The biggest social reform since Medicare is ramping up to full rollout with independent advocacy organisations under huge additional work pressures. Advocates in the NDIS trial suites have been needed to provide advocacy support to people at all stages of interactions with the NDIS:

- pre-planning,
- planning meetings,
- implementation of plans,
- internal reviews,
- external reviews<sup>1</sup>,
- complaints about the NDIS, and
- complaints about service providers,
- as well as (in some trial sites) meeting with NDIA staff on a regular scheduled basis to raise issues/concerns from an advocacy perspective.

In 2015 DANA ran several surveys of advocacy organisation; collecting information about organisational issues, advocacy and the NDIS, and the independent advocacy workforce. These were baseline surveys that will be repeated annually to provide a picture of the independent disability advocacy sector.

Some responses to DANA's NDIS survey:

What are the main triggers for a person needing an advocate in regards to NDIS participation?

Not understanding processes and what NDIA can do; Not being provided with enough knowledge/info to make choices; feeling overwhelmed by the guidelines/legislation; feeling they are not listened to or respected for their lived experience

<sup>&</sup>lt;sup>1</sup> External Reviews: this is the only function where some additional funding has been provided; to one NDAP advocacy organisation in each NDIS trial site to provide External Merit Review (EMR) support for people who are seeking an External Review of an NDIA "reviewable decision" by the Administrative Appeals Tribunal.

#### What difference has it made to the outcome for the client to have an advocate involved?

The client's confidence to make complaints improved as well as consideration of how the client might use the funding to achieve a better outcome (i.e. leave the unresponsive service provider and pursue different options).

# Has your organisation experienced any barriers to providing advocacy to clients who are participants in NDIS?

... people are not receiving information about how to get support and advocacy. The NDIS and other key websites do not mention how to go about appealing decisions in clear enough language.

We have no capacity in the NW and North. We were already at full capacity prior to NDIS

We are doing extra work with no extra funding

# Response to Questions in the Discussion paper

**1.1** How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?

Describing the models of advocacy separately can imply that they are all done very separately by different organisations. The reality is that many advocacy organisations already provide two, three or four models of advocacy but the models are not interchangeable, as they are used for working in different ways with different people. Some advocacy organisations have developed deep expertise in working with the particular target group they are funded for and this is very beneficial for people with disability, their families and carers. If organisations were expected to provide all models, there is a risk of diluting and losing the detailed knowledge and expertise that is within the advocacy sector.

## **1.2** What are the drawbacks?

Having specialist, expert organisations is a positive strength of the advocacy sector. What is possible is to resource advocacy organisations so that they have time to network and collaborate with other advocacy organisations, providing more seamless referral processes for the person needing advocacy.

**1.3** How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?

# DANA recommends that:

The Australian government and State & Territory governments commit additional funding for the provision of independent advocacy. This is urgently required to provide sufficient supply of independent advocacy and to ensure that further gaps in advocacy provision do not develop while the NDIS rolls out in all states and territories.

DANA is funded to **undertake targeted work on current and future workforce needs of independent advocacy organisations**, including the profile of current advocates and attracting, recruiting, qualifications, training, professional development and support needs of the current and future advocacy workforce.

### **2.1** How do we improve access for:

- people with disability from Aboriginal and Torres Strait Islander communities and their families?
- people with disability from culturally and linguistically diverse communities and their families?

- people with disability in rural, regional and remote locations?
- people who are very socially isolated including those with communication difficulties and those in institutional care?

The Review has received detailed information from organisations that specialise in providing advocacy for all of these population groups. This experience must be taken into account as the Review proceeds, and the targeted workshops must bring together the relevant organisations to harness their collective experience and jointly plan ways to increase access to advocacy for people with disability who have specific additional barriers.

NDAP organisations currently ensure that their staff receive cultural awareness training appropriate for the cultures with whom they work, also including working with Aboriginal and Torres Strait Island peoples. More needs to be done, however, especially in regards to the recruitment of advocates with the relevant language and cultural experience and background.

#### DANA recommends that:

 Detailed consultation with the advocacy sector in the development of any new funding formula for distribution of funding within the NDAP, to allow opportunity for specific contributions arising from the experience of the organisations, in particular about any weightings that may be developed to address additional barriers, such as remoteness, language and cultural background, Aboriginality, communication needs, and current or past institutionalisation.

**2.2** What are the strategies or models that have worked? What are the strategies that do not work?

Submissions from many advocacy organisations to this Review have provided a good overview of the strategies that have worked and not worked and these should be workshopped further as the Review proceeds. DANA supports the input of those with specialist knowledge in these areas as experts in the delivery of independent advocacy to the various groups noted above. We would encourage the inclusion of lesbian, gay, bisexual, transgender and queer within target communities requiring additional support.

**3.1** What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?

Advocacy organisations are actively participating as much as they can in regional, metropolitan and state-wide mechanisms that operate in each state and territory. The data collected from the advocacy organisations annually through NDAP reporting could be shared widely by DSS to facilitate awareness of advocacy and the specific systemic issues that are being addressed by the advocacy agencies.

DANA recommends that DSS work with the advocacy sector to plan for relevant data collection and use. Organisations need to know in advance what pieces of information are required, and be able to plan to build it into their systems.

DANA has scoped a systemic advocacy portal that could be used as a clearinghouse of systemic advocacy, strengthening knowledge and awareness in the sector about which other organisations have a shared interest in each systemic issue. This would enhance collaboration between the organisations and lead to better systemic advocacy outcomes.

**3.2** How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as:

- disabled people's organisations (DPOs)
- the Australian Human Rights Commission
- Ombudsman organisations
- aged care advocacy organisations
- state disability advocacy organisations
- peak bodies?

Other organisations that could be added to this list include university research centres.

For disability advocacy organisations to work with all of the organisations above requires access to targeted information, shared training, and attendance at relevant conferences. DANA can fulfil the role of being the conduit to provide the relevant information to the advocacy organisations. The DANA Conferences have proven to be the best way to get advocates together from around Australia, to share experiences, learn together, and discuss topics of common interest.

- The Australian government commits recurrent funding for DANA as the national peak body for independent advocacy organisations. The government funds a national representative organisation for disability service providers recognising that the voice of the industry needs to be heard and to have a place in policy development. Equally, the legitimate, collective voice of the independent advocacy organisations requires ongoing funding that acknowledges the value of this specific, detailed, and wide-ranging perspective.
- DANA is funded sufficiently to build and develop capacity within independent advocacy organisations, disseminate information, run advocacy-related conferences and events, collaborate in research, provide human rights-based analysis relevant to

disability issues, participate in consultations & raise awareness of the value of independent advocacy.

**4.1** What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimised?

Independent advocacy organisations have always worked to avoid, minimise and manage conflicts of interest. NDAP organisations are independently certified under a Quality Assurance process that has just completed the first 3 year cycle of audits. The organisations are audited against the National Standards for Disability Services and a strong focus in the audits is demonstrating awareness of and management of potential conflicts: detailed policies; conflict of interest registers for staff, Board members, volunteers; processes for dealing with conflicts if they arise.

DANA is working with the advocacy sector to gather the existing structures, systems and collective wisdom and experience about conflicts of interest, and creating opportunities for sharing and discussion.

**4.2** How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?

As mentioned earlier it is not yet completely clear what the gaps will be between supports provided by the NDIS and advocacy funded by the NDAP.

- DSS and the NDIA jointly undertake work to resolve the issues that require clarification about how decision support and safeguard supports will be practised, funded and allocated within the NDIS. That DANA and the independent advocacy sector are active participants in this work, which would include monitoring and evaluating outcomes for consumers of those advocacy organisations that register as providers under NDIS to deliver support coordination or similar functions, under advocacy principles.
- that the development of policy about decision supports recognises that independent advocates have a long history of providing decision support as an integral part of advocacy and this experience must inform the development and practise of this important policy area.
- that the guidelines and policy about decision support within the NDIS be developed to be coherent with the decision-making principles articulated by the Australian Law Reform Commission -
  - 1. Every adult has the right to make decisions that affect their life and to have those decisions respected.

- 2. Persons who may require support in decision-making must be provided with the support necessary for them to make, communicate and participate in decisions that affect their lives.
- 3. The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives
- 4. Decisions, arrangements and interventions for persons who may require decision-making support must respect their human rights.
- Funding for Human Rights education be made available nationally for advocacy organisations.
- Any changes to the NDAP are consistent with the Quality and Safeguarding Framework and the Information, Linkages and Capacity Building Policy for the NDIS, so that any proposed changes in the delivery of independent advocacy and advocacy-type activities happens with adequate time for transition, if necessary, by advocacy organisations to different structures, program requirements, reporting requirements etc.
- 4.3 What policies and strategies do we need to protect the rights of people with disability?

- Further consultation needs to include direct focus groups with people with disability, organised with and through their representative organisations and DPOs, including with members of Self Advocacy Groups, using Easy English consultation questions and structured to allow enough time for good input.
- Any restructure of the NDAP ensures as far as possible that choice of advocacy provider is available, in the same way that the NDIS provides choice to participants.
- Arising from this Review, if the selection process DSS decides to use to determine
  the next funding round for NDAP is a Tender process; DANA recommends a select
  tender for existing advocacy organisations with deliberate exclusion of organisations
  that provide traditional disability services, such as accommodation support or
  community access.
- Any such selection process should be open to applications from state and territory funded advocacy organisations, many of whom have equally as long a history of providing independent advocacy as the NDAP organisations.
- 5.1 What forms of legal review and representation do people with disability need most?

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# Legal services incorporating specialist disability expertise during justice processes

People with disability have little support in the legal system, especially at the initial arrest stage, and face difficulties in accessing justice, due to police, court and community perceptions concerning the abilities and capabilities of people with disability to be good witnesses. People with disability<sup>2</sup> are significantly over represented in the criminal justice system as both offenders and victims.<sup>3</sup> In several other areas of the justice system people with disability represent large groups of affected people including in child protection, guardianship, and tenancy matters. Yet there are very few specialist disability response legal services anywhere in Australia, and few that have a capacity to respond to the variety of matters that the disability population faces.<sup>4</sup> For instance,

The Intellectual Disability Rights Service is the ONLY service in NSW that is funded to support people with intellectual disability in the criminal justice system and whilst client intake increases steadily funding does not. There continues to be a high rate of victimisation, violence, and assault of people with intellectual disabilities.<sup>5</sup>

Throughout various points in justice processes, inflexible systems or procedures often fail to respond to a person's disability and their associated needs, or the identification of their disability leads to discrimination against them.<sup>6</sup>

When people with disability are able to access legal representation, lawyers are often illequipped to respond to their particular individual needs; for example, allowing the client time to process information, or communicating in ways that support their comprehension and involvement. People with disability may need "more time to understand and answer questions or... a support person to explain things to them and ensure that they are not overwhelmed by the stress of a new and confronting situation (like a court or police station)"<sup>7</sup>

In their work with people with disability, independent advocacy organisations have often found that police officers, lawyers, and court staff do not have specific skills for working with people with disability, despite the best of intentions. Usually, justice professionals also lack the time that is required to ensure full participation by a person with significant cognitive or communication barriers.<sup>8</sup>

<sup>&</sup>lt;sup>2</sup> The *Convention on the Rights of Persons with Disabilities* includes people with psychosocial disability.

<sup>&</sup>lt;sup>3</sup>Australian Human Rights Commission. (2014). *Equal before the law: Towards disability justice strategies*. https://www.humanrights.gov.au/our-work/disability-rights/publications/equal-law

<sup>&</sup>lt;sup>4</sup> In the ACT, the only disability specialist response is the Disability Discrimination Legal Centre which focusses on responding to matters covered by the *Disability Discrimination Act* 1991.

<sup>&</sup>lt;sup>5</sup> From surveys conducted to inform DANA (2014) *Progress on the National Disability Strategy 2010-2020: Disability Advocacy Network Australia Engagement.* 

<sup>&</sup>lt;sup>6</sup>For instance, being assessed as having cognitive impairment, and subsequently being found unfit to plead, directly contributes to the indefinite detention of people with disabilities: Aboriginal Disability Justice Campaign, 'Position Statement on the Inappropriate Incarceration of Aboriginal People with Cognitive Impairment', (Position Paper, People With Disability Australia, October 2008) <www.pwd.org.au/systemic/adjc.html>. Sotiri, M, McGee, P, & Baldry, E (2012) *No End in Sight. The Imprisonment and Indefinite Detention of Indigenous Australians with a Cognitive Impairment*. Sydney: University of NSW.

Fogarty, B. (2010) 'Improving legal representation for people with intellectual disability', Precedent 96.

<sup>&</sup>lt;sup>8</sup> Advocacy for Inclusion (2015) *Submission to the ACT Budget 2016-17*, p9; Productivity Commission *Access to Justice Arrangements* – Submissions <a href="http://www.pc.gov.au/inquiries/completed/access-justice/submissions">http://www.pc.gov.au/inquiries/completed/access-justice/submissions</a>; Australian Human Rights Commission. (2014). *Equal before the law: Towards disability justice strategies*. Submissions <a href="https://www.humanrights.gov.au/our-work/disability-rights/access-justice-submissions">https://www.humanrights.gov.au/our-work/disability-rights/access-justice-submissions</a>

DANA's 2014 consultation with disability advocates for *Progress on the National Disability Strategy 2010-2020: Disability Advocacy Network Australia Engagement*<sup>9</sup> highlighted the importance of:

- Ensuring "access to support person for people with cognitive disabilities in courts and police stations, along the lines of the Criminal Justice Support Network in NSW or the Independent Third person in Victoria.
- "Funding to advocacy services to better support people with disabilities participating in the justice system"
- Implementing "training for solicitors in working effectively with people with cognitive disability, (along with) adequate funding to allow additional time to represent a person with cognitive impairment."
- Funding "legal representation by lawyers and by paralegals for appearances before mental health tribunals ... and also for people subject to restrictive practices, who cannot self-represent without support to do so." 10

# Support to make complaints

"Improving the reach and effectiveness of all complaint mechanisms" is listed in the National Disability Strategy as an area for future action. The experience of the advocacy sector is that complaints mechanisms can play a crucial role in effecting change and improvements in disability care and supports, and in other service systems. Far too often, however, the capacity to pursue a complaint through existing mechanisms is hampered by lack of access to advocacy (including legal advocacy), lack of resources within complaints-handling bodies, inflexible criteria for the complaints that each type of body may review or a lack of effective internal complaints mechanisms.

People with disability do not always have independent access to the telephone or webbased information, and may be uninformed about their rights to make complaints or the need to seek out legal information or assistance. Marginalised people with disability will need advocacy support to voice their concerns, make complaints and address legal problems.

#### Support during alternative dispute resolution processes

Alternative Dispute Resolution (ADR) processes present options for less formal and less costly resolution of disputes. However, ADR services are not equally accessible to people with disability. Furthermore, ADR processes can present risks where one party is substantially weaker in influence or ability to conduct negotiation. Safeguards are crucial to ensure the vulnerable party is protected from being marginalised or pressured into giving concessions or accepting less. Disputants with disabilities should not experience the

<sup>&</sup>lt;sup>9</sup> DANA (2014) *Progress on the National Disability Strategy 2010-2020: Disability Advocacy Network Australia Engagement.* 

<sup>&</sup>lt;sup>11</sup> Submission 24, quoted in Draft Report, p273.

<sup>&</sup>lt;sup>12</sup> Mary Anne Noone (2011) 'ADR, Public Interest Law and Access to Justice: The Need for Vigilance', 37 (1) *Monash University Law Review*, p57.

process as disempowering or intimidating, and should have ready access to independent advocacy services and a range of support options.<sup>13</sup>

# 5.2 What barriers prevent people with disability from accessing justice?

The barriers to justice experienced by people with disability extend across a range of areas. In 2012, the Legal Australia-Wide Survey conducted by the Law and Justice Foundation of New South Wales examined access to justice and legal need and found people with disability stood out as a disadvantaged group across all jurisdictions. Not only are people with disability:

"more likely to experience legal problems, but the wide range of legal problems they face may impact negatively on their lives and further entrench their social exclusion". 16

Much has been published in recent years on the complex barriers preventing people with disability from accessing justice in both civil and criminal settings:

- Australian Human Rights Commission. (2014). *Equal before the law: Towards disability justicestrategies.* <sup>17</sup>
- Australian Law Reform Commission, Equality, Capacity and Disability in Commonwealth Laws, ALRC Report 124 (2014)<sup>18</sup>
- Productivity Commission, Australian Government (2014) Access to Justice Arrangements – Draft Report, p34. 97, 105, 148-9, 170-171, 272-273, 426, 430, 582-583, 611, 627-632, 663, 854-855.
- Camilleri. M. (2010) Disabled Justice: Why reports of sexual assault made by adults with cognitive impairment fail to proceed through the justice system.
- Coumarelos, C., Macourt, D., People, J., McDonald, H. M., Wei, Z., Iriana, R., & Ramsey, S. (2012). Legal Australia-wide survey: Legal need in the Australian Capital Territory (Vol. 8). Law and Justice Foundation of New South Wales

Disability advocates are often dealing with matters that have a legal dimension. In DANA's 2014 survey of advocates, the majority of respondents identified access to justice for people with disability as having shown little or no significant improvement since 2011, when the

<sup>&</sup>lt;sup>13</sup> Jim Simpson, (2002) *Guarded Participation: Alternative Dispute Resolution and People with Disabilities*, Report on a research project carried out with funding from the Law and Justice Foundation of NSW.

<sup>&</sup>lt;sup>14</sup> Productivity Commission (2004) *Review of the Disability Discrimination Act 1992- Inquiry Report*, 3 April 2004, p 248-253. Coumarelos, C. et al. (2013), *Law and disorders: illness/disability and the experience of everyday problems involving law,* Justice Issues Paper 17. Law and Justice Foundation of New South Wales.

<sup>14</sup> Ibid. 19.

<sup>&</sup>lt;sup>15</sup> Coumarelos, C. et al. (2012), *Legal Australia-wide survey: Legal need in the Australian Capital Territory* (Vol. 8). Law and Justice Foundation of New South Wales, xv. <sup>16</sup> Ibid. 19.

<sup>17</sup> https://www.humanrights.gov.au/our-work/disability-rights/publications/equal-law

<sup>&</sup>lt;sup>18</sup>https://www.alrc.gov.au/publications/7-access-justice

<sup>&</sup>lt;sup>19</sup> For final Report see: http://www.pc.gov.au/inquiries/completed/access-justice/report

National Disability Strategy commenced.<sup>20</sup> A substantial proportion of people with disability cannot afford to secure legal services and legal assistance services are not meeting their needs. The high costs of accessing justice services impacts disproportionately on the lives of people with disability, as they often experience multiple forms of disadvantage, disempowerment and human rights abuse. Cultural and attitudinal issues among legal professionals and in the broader community, as well as the nature of the legal system, further disadvantages those with a real or perceived lesser capacity to participate in the highly formalised and ritualised structures of the justice system. Advocacy agencies are not sufficiently resourced to support the rights and needs of clients:

In many areas there is still no access to individual advocacy for people with disability. Grants of Legal Aid do not recognise that it is inevitable that if a solicitor is to adequately assist a person with cognitive impairment, they will need to spend more time. Hence they often do not go the extra mile to provide effective representation/casework.<sup>21</sup>

People with disabilities are less likely to afford legal representation and depend on under resourced Legal Aid to accept their application. This means that people needing legal representation who may be less than likely to have success in a case or who are not in absolute crisis are often not accepted for Legal Aid. Advocacy is substantially underfunded and our organisation has had to close our books and turn away significant numbers of intakes as we are beyond capacity. We are only able to respond to people in absolute crisis.<sup>22</sup>

DANA would like to acknowledge the excellent work done by many Community Legal Centres, including specific disability legal services, who adapt their practice to be able to advise and support people with disability and in some cases have made it their mission to support and represent people with disability. We also recognise the importance of Legal Aid services around Australia in making legal support more accessible. Without these, thousands of people with disability would have been unable to access justice, exercise their rights or pursue crucial precedence setting cases. The sad truth remains however that the capacity of these services is highly constrained and thousands of other people with disability remain unable to challenge the sometimes horrific rights abuses of which they have been victims.

Advocacy for Inclusion in the ACT has recently argued that jurisdictions have been relying on generic justice solutions to respond to people with disability, (many of whom have cognitive impairments or significant communication barriers and complex support needs). While many of these existing solutions are high quality for general purposes, they also face substantial demand, and so they struggle to respond appropriately to many people with disability. <sup>23</sup>

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<sup>&</sup>lt;sup>20</sup> 11 of 16 respondents to Rights Protection, Justice and Legislation survey of advocates to inform DANA (2014) *Progress on the National Disability Strategy 2010-2020: Disability Advocacy Network Australia Engagement.* 

<sup>&</sup>lt;sup>21</sup> Italicised, indented paragraphs are quotes from responses to surveys conducted to inform DANA (2014) *Progress on the National Disability Strategy 2010-2020: Disability Advocacy Network Australia Engagement.* 

<sup>23</sup> Advocacy for Inclusion (2015) Submission to the ACT Budget 2016-17, p5

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The lack of a specialist disability response means people with disability do not have equal access to justice. The key contributing factor to the current situation is a long term failure by governments to recognise the considerable disadvantage faced by people with disability in accessing justice on equal terms to the broader population.<sup>24</sup>

DANA recommends that the Australian Government act on the recommendations of the Australian Human Rights Commission, the Australian Law Reform Commission, and the Productivity Commission, and on the intentions of its National Disability Strategy, to reduce the significant barriers preventing people with disability from accessing justice.

## 5.3 What models of legal advocacy are most effective?

The most effective model of legal advocacy is one that provides:

# Advocacy support when interacting with justice systems

Advocacy draws attention to matters that have been overlooked or dismissed through justice processes. Advocates often work to make sure the lawyer understands relevant lived experience and its importance, or may communicate directly to prosecutors, magistrates and judges to ensure they are apprised of the relevant facts and those matters that might not ordinarily be canvassed or understood. Advocates can often provide the detailed knowledge of the individual client, and play a role in interpreting meaning to and from the person with cognitive impairment or communication barrier.

Advocacy has been alongside many vulnerable people with intellectual disability in relation to child protection and criminal matters.<sup>25</sup>

Increased capacity in the advocacy sector to respond to the needs of people with disability before they reach crisis stage would provide support contributing to the avoidance of legal disputes or criminal matters before they arise for people with disability.

This was recognised by the Australian Human Rights Commission as imperative for disability justice strategies in Action 4.3.3: "Provide access to advocacy and legal services with disability expertise regardless of place of residence or geographical location".

# Legal education for people with disability, justice professionals and wider community

During arrest and interrogation, some suspects with disabilities will struggle to understand their legal rights, including the right to silence, especially where no specific communications

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 $<sup>^{24}</sup>$  Advocacy for Inclusion (2015) Submission to the ACT Budget 2016-17, p6.

<sup>&</sup>lt;sup>25</sup> From surveys conducted to inform DANA (2014) *Progress on the National Disability Strategy 2010-2020:* Disability Advocacy Network Australia Engagement.

support is provided.<sup>26</sup> These barriers are, in turn, likely to influence the sentencing stage, contributing to the high number of detention orders imposed on people with disability.<sup>27</sup> A person's disability is not always readily evident - and police, and other first responders, often fail to identify its presence.<sup>28</sup>

This highlights the importance of **Self Advocacy** which educates people with disability to identify when their rights are being violated and empowers them to speak up.

Resources and training are delivered by dedicated legal advocacy organisation, such as Intellectual Disability Rights Service<sup>29</sup> and Villamanta Disability Rights Legal Service<sup>30</sup>, and by the broader independent advocacy sector, on people's legal rights and remedies across a range of issues and areas of law.<sup>31</sup>

# Holistic approach to problems

The Law and Justice Foundation of NSW, 32 has stated:

the multiple legal and non-legal problems faced by people with a disability indicate that they may require both legal assistance and broader non-legal support in order to achieve complete resolution of their legal problems.<sup>33</sup>

Disability advocates commonly pursue a holistic problem-solving approach in their work with clients, responding to the individual's needs by identifying and addressing both legal and non-legal issues of concern. Advocates are experienced at assisting clients who do not perceive the legal dimensions of their problems, or understand how the law applies to their situation, and are therefore unlikely to seek out and instruct a legal adviser. The client intake processes of advocacy agencies often resemble "legal health checks". 34

<sup>&</sup>lt;sup>26</sup> Bartels, L. (2011). *Police Interviews with Vulnerable Adult Suspects*. Research in Practice Report No. 21. Australian Institute of Criminology, Canberra, ACT. 13p.

<sup>&</sup>lt;sup>27</sup> Cockram, J. 'People with an Intellectual Disability in Prisons' (2005) 12 *Psychiatry, Psychology and Law* 163, 170.

Susan Hayes, 'A Review of Non-custodial Interventions with Offenders with Intellectual Disabilities' (2005) 17 *Current Issues in Criminal Justice* 69, 71. M Henshaw and S Thomas, 'Police Encounters with People with Intellectual Disability: Prevalence, characteristics and challenges' (2011) *Journal of Intellectual Disability Research* 1.

<sup>&</sup>lt;sup>29</sup> In New South Wales, Intellectual Disability Rights Service have done excellent work training people with intellectual disability about their legal rights and obligations, and also the broader community. For instance, on their website you will find factsheets and resources aimed at educating:

lawyers working with clients with intellectual disability

police officers dealing with sexual assault victims with intellectual disability

people with disability (and their supporters) wanting to make a complaint about service providers.

See IDRS website: <a href="http://www.idrs.org.au/education/for-pwid.php">http://www.idrs.org.au/education/for-pwid.php</a> and their website on NSW's child protection system: <a href="http://idrs.org.au/makingsense/">http://idrs.org.au/makingsense/</a>

Villamanta Disability Rights Legal Service offers free access to Your Rights Your Choices - an easy to read plain English booklet about legal rights for people who have an intellectual disability in Victoria. See website: http://www.villamanta.org.au/Main.asp? =Resources

<sup>&</sup>lt;sup>31</sup> See for example, NSWCID on Criminal Justice <a href="http://www.nswcid.org.au/what-we-do/criminal-justice.html">http://www.nswcid.org.au/what-we-do/criminal-justice.html</a>; Advocacy for Inclusion's Guardianship fact sheets <a href="http://advocacyforinclusion.org/index.php/resources/guardianship-resources">http://advocacyforinclusion.org/index.php/resources/guardianship-resources</a>; QADA's Mental Health Act training: <a href="http://www.qada.org.au/understanding-mental-health-guardianship-training">http://www.qada.org.au/understanding-mental-health-guardianship-training</a>; Youth Disability Advocacy Service (Victoria) Rights Hub: <a href="http://youthdisabilityrights.org.au/">http://youthdisabilityrights.org.au/</a> etcetera

<sup>&</sup>lt;sup>32</sup> Productivity Commission, Australian Government (2014) Access to Justice Arrangements – Draft Report, p171.

<sup>&</sup>lt;sup>33</sup> Coumarelos, C., Macourt, D., People, J., McDonald, H.M., Wei, Z., Iriana, R. and Ramsey, S. 2012, *Legal Australia-Wide Survey: Legal Need in Australia*, August, Law and Justice Foundation of NSW, Sydney. 233.

<sup>&</sup>lt;sup>34</sup> See Recommendation 5.3 - Productivity Commission, Australian Government (2014) Access to Justice Arrangements: "A greater use of holistic services, outreach, training of non-legal community workers to identify legal problems, and legal health checks would identify those who need additional assistance and help them to navigate the civil justice system."

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Independent advocacy agencies sometimes operate outreach services to reach vulnerable people living in institutions, or in remote or regional areas, and often actively refer clients to other services, enhancing collaboration and integration. However, the performance of these outreach, referral and screening functions by advocacy agencies is often severely constrained by shortages of resourcing and capacity, related to the chronic under-funding of the sector. Dedicated funding to independent advocacy agencies would therefore be needed for comprehensive delivery of legal health checks and for legal problem identification training for non-legal advocates.<sup>35</sup>

DANA believes that improved access to disability advocacy, including non-legal advocacy would contribute to improved equity and access to justice, to the achievement of earlier and lower cost civil dispute resolution and not least to crucial support for people with disability that would contribute to the avoidance of legal disputes before they arise. Similarly, ensuring equal treatment for people with disability -whether as victims of crime, offenders or participants in the criminal justice system – has the potential for "considerable economic savings... by preventing violence and providing early diversion and support". <sup>36</sup>

# Specialist support to aid effective communication between people with disability and justice professionals

In different ways the independent advocacy sector has endeavoured to ensure people with disability can participate equally in justice process and achieve just outcomes.

The Criminal Justice Support Network is a service of Intellectual Disability Rights Services in New South Wales – it provides telephone legal advice, support at court in criminal matters and support at police stations.<sup>37</sup>

Queensland Advocacy Inc. provides a Justice Support Program, which is an individual advocacy service supporting people with disability (particularly intellectual impairment), charged with offences through the criminal justice system

Other advocacy organisations run services that provide advice, support and representation in certain tribunal matters.<sup>38</sup>

Although there are reforms underway in some States and Territories to make justice systems more accessible to people with disability, lawyers, police officers and other relevant personnel are not, and cannot reasonably be expected to become, experts in disability or proficient in responding to the various needs of this group. Rather, access to specialist support to assist communication and comprehension in justice settings would enable people with disability to meaningfully participate in legal processes. People working in the justice system must be trained in identifying when specialist expertise and support is required, and have access to supports to call in for assistance.<sup>39</sup>

<sup>35</sup> Ibid.

<sup>&</sup>lt;sup>36</sup> Graeme Innes –Disability Discrimination Commissioner (2014) Foreword - *Equal before the law: Towards disability justice strategies.* 

<sup>&</sup>lt;sup>37</sup> IDRS – CJSN: <a href="http://www.idrs.org.au/support/support.php#about\_cjsn">http://www.idrs.org.au/support/support.php#about\_cjsn</a>

For example; Villamanta: <a href="http://www.villamanta.org.au/main.asp?">http://www.villamanta.org.au/main.asp?</a> = Services Advocacy Tasmania: <a href="http://www.advocacytasmania.org.au/mhtrs.htm">http://www.advocacytasmania.org.au/mhtrs.htm</a> Queensland Aged and Disability Advocacy: <a href="http://www.qada.org.au/services/guardianship-advocacy">http://www.qada.org.au/services/guardianship-advocacy</a>

<sup>&</sup>lt;sup>39</sup> Advocacy for Inclusion (2015) Submission to the ACT Budget 2016-17, p10.

For instance, Advocacy for Inclusion has been trialling a model in which both legal and disability specialist practitioners can work alongside each other to more effectively achieve outcomes for the person with disability – the lawyer focuses on the legal outcomes, while the advocate ensures two way disability communication and the fullest possible engagement by the person with disability.<sup>40</sup>

### Importance of systemic reforms

The Productivity Commission has articulated the great value of the strategic advocacy and law reform efforts of legal aid commissions and community legal centres. Similarly, the daily experience of disability advocates in assisting disadvantaged clients is harnessed to identify systemic issues and provide input into reform processes. The advocacy sector plays a vital role in driving change on a broader level:

Disability advocacy organisations have been at the forefront of facilitating and developing supported decision making initiatives.

Some disability accommodation service providers have shown increased awareness and understanding of violence in supported accommodation for people with disabilities and have shown improvement in taking appropriate action, although substantial further improvement is required. This has been achieved through advocacy at individual and systemic levels.

Advocacy organisations have been involved in inquiries into access to justice for people with disabilities, helping to shed light on the issues on the ground.<sup>42</sup>

In the context of access to civil dispute resolution and legal services, the Productivity Commission has recommended that: "Australian, State and Territory Governments should provide funding for strategic advocacy and law reform activities that seek to identify and remedy systemic issues and so reduce demand for frontline services." <sup>43</sup>

DANA recommends that any alteration to the current arrangements for legal advocacy must be informed by recognition of

- the major gaps existing in advocacy supports available to people with disability interacting with justice systems
- the current efforts of independent disability advocacy organisations to educate people with disability, justice professionals and the wider community about legal rights and issues relevant to disability (on limited funding);<sup>44</sup>
- the holistic problem-solving approach taken by the independent disability advocacy sector in addressing people's legal and non-legal problems;
- the importance of specialist support to aid effective communication between people with disability and justice professionals;

See further Advocacy for Inclusion (2015) Submission to the ACT Budget 2016-17,p15.http://advocacyforinclusion.org/index.php/2014-09-22-05-11-32/publications-home/budget-submissions

<sup>&</sup>lt;sup>41</sup> Productivity Commission, Australian Government (2014) *Access to Justice Arrangements – Draft Report*, 622-625.

<sup>&</sup>lt;sup>42</sup> From surveys conducted to inform DANA (2014) *Progress on the National Disability Strategy 2010-2020: Disability Advocacy Network Australia Engagement*.

<sup>&</sup>lt;sup>43</sup> Recommendation 21.1, Access to Justice Arrangements Inquiry Report

<sup>&</sup>lt;sup>44</sup> Including through Self Advocacy programs

- the valuable connection between legal advocacy and systemic advocacy, which aims to change the systems that impact on the legal rights of people with disability; and
- the need for further consultation with the sector.

# Appendix A

**Testimonials from clients of advocacy services** (collected across all states and territories) demonstrate the range of potential benefits to an individual:

...if I, and people like myself, do not have an advocate, services ignore me and people just fob me off and I go nowhere.

So the outcome with my advocate has been good, positive and helped us move forward.

I would like to thank ...my advocate for all her hard work in resolving all my issues and empowering myself when I thought it was not possible.

...made me feel heard and understood.

My self-esteem has been built up immensely and I feel I have a right.

Having their support meant I could sort out most of my problems myself, and that felt great.

They really saved my life – I was really in despair and they helped me move forward and showed me a clear pathway.

My advocate has been an inspiration to me and has helped me in so many ways. She has the experience, professionalism and knowledge to guide me in directions I never thought possible.

Absolutely vital. Without independent advocacy I wouldn't have access currently to the place I'm living or to the package of support (Vic DHS ISP) that lets me live independently in the community

**Responses from family members and carers** of people with disability to DANA Survey: *Independent advocacy's role in the NDIS Quality and Safeguarding Framework,* April 2015

[advocates] inform people about their entitlements and empower them with all the information they need to make informed decisions. They 'bridge' between the service and the people, and bring a specialist understanding of the systems and processes. They help people understand what their entitlements are, what they can expect, and how to navigate the system and monitor quality assurance. They stand up for and with people who are vulnerable. It's sad that we even need such a role and in an ideal world we wouldn't but unfortunately this isn't an ideal world and the role of independent advocacy is essential

Advocacy is essential to the on-going success of people with a disability and their families to access equal rights to education, health, employment, housing etc in Australia. Advocacy groups can represent vulnerable people and speak up for them when no one else will.

[The Citizen Advocacy organisation] have given me a reason to go on loving and caring. Because their support and care gives hope and courage. With encouragement we won't lose the strength to carry on

It keeps the bastards honest and makes them accountable. They cannot brush you aside when there are issues to be dealt with. It stops the major players from doing their normal thing of not responding at all.

Without independent advocacy choices about services could not be acted on.

We need independent advocacy as it is difficult to be aware of all our issues and rights as a parent, with changing legislation. An advocate present in meetings is able to explain our feelings better at times than parents can... parents still need to work within the system, so do not wish to cause difficulties

# Appendix B

# Information on the models of advocacy, referred to in the Discussion paper

Individual Advocacy

Under the National Disability Advocacy Program (NDAP), individual advocacy seeks to uphold the rights and interests of people with all types of disabilities on a one-to-one basis by addressing instances of discrimination, abuse and neglect. Individual advocates work with people with disability on either a short-term or issue-specific basis. Individual advocates:

- work with people with disability requiring one-to-one advocacy support;
- develop a plan of action (sometimes called an individual advocacy plan) in partnership with the person with a disability that maps out clearly defined goals;
- educate people with disability about their rights; and
- work through the individual advocacy plan in partnership with the person with a disability.<sup>45</sup>

The most recent national resource on disability advocacy is a video created by the Department of Social Services in 2013 with the collaboration of NDAP funded advocacy organisations. In a case study, an advocate from People with Disability Australia in Queensland assists client Rebecca with the abusive situation in her group home, and ultimately secures accommodation for her to live independently in the community, with appropriate supports.

The individual advocate Luke "took a proactive role in finding a positive solution" and met with service providers, domestic violence support agencies, police and local ministers "to try to extract Rebecca from this abusive situation."

Matthew Bowden from PWDA highlights the value of the advocate being independent from others involved:

"One of the essential parts of individual advocacy is that it's independent and that's important for the advocate to be not influenced by other factors but to only be on the side of the person with disability and only speak representing their interests and what their fundamental needs and issues are."

"Firstly, I tried several times to get issues resolved within the organisation, and they did fob me off and I was getting nowhere. I didn't even know that there was advocacy available, and so I decided to give it a try."

It's totally changed everything. I have my own life back, I was really stressed living in that situation and depressed, and I needed to get out of it, and the advocacy was the only way that would make it possible."

<sup>&</sup>lt;sup>45</sup> *Models of Disability Advocacy,* Department of Social Services Website.

Access to individual advocacy services is extremely valuable for people with disability experiencing, or at risk of, abuse, neglect or exploitation.

# Self Advocacy

Self advocacy supports people with disability to advocate on their own behalf, to the extent possible, or on a one-to-one or group basis.

# Through self advocacy:

- advocates work with people with disability to develop their personal skills and self-confidence to enable them to advocate on their own behalf.
- people with disability are educated about their rights.

Kathryn, who features in the video, and has attended self-advocacy training and group meetings at Advocacy for Inclusion, explains how learning new skills has helped her:

I used to get angry, I'd slam doors because I didn't know how to express myself, how I was feeling.... now I know how to express how I feel. I've learnt how to stick up for my rights...

It means I get to speak to the staff to resolve my problems and I feel happier ...

Self advocacy is good because it helps you understand what you're going through.<sup>47</sup>

Self advocacy training allows people with disability to gain and practice skills to help them voice complaints and have their say, to recognise when their human rights are being violated, and to report abuse or neglect that occurs.

### Citizen Advocacy

Seeks to support people with a disability by matching them with people recruited purposefully from the community. Some of the matches made may last for life. Through citizen advocacy:

- people with disability who are isolated with no family or community supports or networks are sought out
- citizen advocates are encouraged to represent the interests of a person with a disability as if they were their own, and be free from conflict of interest- they are recruited, trained and supported by a coordinator who manages the work of the citizen advocacy agency.<sup>48</sup>

Strong relationships and community connections reduce a person's vulnerability to abuse, and provide support and guidance to remedy abuse when it occurs.

Citizen Advocacy coordinator: A citizen advocate can support the person to report the abuse and will continue to stand by them, encouraging their much needed self-esteem. People need allies that make them feel valued, when they have been abused.

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<sup>&</sup>lt;sup>46</sup> *Models of Disability Advocacy*, Department of Social Services Website.

<sup>&</sup>lt;sup>47</sup> Department of Social Services (2013) *Self Advocacy – The National Disability Advocacy Program* video. Quote from Self Advocate, ACT.

<sup>&</sup>lt;sup>48</sup> *Models of Disability Advocacy,* Department of Social Services Website.

I had been banging my head against a wall – for me, they were a lifesaver.<sup>49</sup>

- can protect those that are most vulnerable from harm & even death; having a person that will be there for you in your life in an un-paid capacity (such as a citizen advocate) can be the most powerful relationship in protecting well-being. - people are scared that if they say anything about their service, then they'll lose the service - advocates can help ensure this doesn't happen. <sup>50</sup>

# Family Advocacy

Family advocacy organisations work with parents and family members to enable them to act as advocates with and on behalf of a family member with disability. Family advocates work with parents and family members on a short-term or an issue-specific basis. Family advocates work within the fundamental principle that the rights and interests of the person with disability are upheld at all times.

### Through family advocacy:

- family members are provided with advice and support;
- the person with disability is assisted via the family member being directly supported by the agency to advocate on their behalf.<sup>51</sup>

Parents and relatives naturally adopt the role of advocating for the human rights of their family member with a disability. There are few organisations in Australia specifically dedicated to supporting and resourcing family advocacy, however other advocacy organisations also inform and support families in their advocacy efforts.

Family Advocacy provided us with information and resources that enabled us to create a vision for Daniel and to be in a position to maintain that vision and follow that through.<sup>52</sup>

People with disability who have close connections with family members are better shielded from abuse, neglect or exploitation than those who do not have ongoing family contact. Supportive relationships and community involvement can reduce isolation and vulnerability but cannot guarantee protection against abuse. In this situation, parents or other relatives seek justice for their loved one and may enlist the help of an independent advocacy organisation.

# Legal Advocacy

Seeks to uphold the rights and interests of people with all types of disabilities on a one-to-one basis by addressing legal aspects of instances of discrimination, abuse and neglect.

# Legal advocates may:

 provide legal representation for people with disability as they come into contact with the justice system;

<sup>&</sup>lt;sup>49</sup> Carer of a person with disability, NSW. Telephone conversation, 29 April 2015.

<sup>&</sup>lt;sup>50</sup> Disability advocate. QLD.

<sup>&</sup>lt;sup>51</sup> Models of Disability Advocacy, Department of Social Services Website. Quote from Family Advocate, NSW.

- pursue positive changes to legislation for people with disability; and
- assist people with disability to understand their legal rights.53

For a person with disability who has been raped or sexually assaulted or experienced other forms of abuse or violence in residential or institutional settings, access to legal information and advocacy support may be particularly crucial to securing a legal remedy and getting justice. (For instance, ensuring prosecution and conviction of the perpetrator; obtaining compensation from a negligent service provider)

# Systemic Advocacy

Under the National Disability Advocacy Program (NDAP), systemic advocacy agencies:

- pursue positive changes to legislation, policy and service practices in partnership with groups of people with disability, advocacy agencies and other relevant organisations;
- seek to address barriers and discriminatory practices to produce long-term positive changes.

In the context of access to civil dispute resolution and legal services, the Productivity Commission recently recommended that: Australian, State and Territory Governments should provide funding for strategic advocacy and law reform activities that seek to identify and remedy systemic issues and so reduce demand for frontline services.<sup>54</sup>

Independent advocacy at the systemic level is critical to achieving and safeguarding good policy outcomes that affect the lives of people with disability<sup>55</sup>

Independent advocacy also ensures that systems designed to protect and support people are doing what they say they will do. For example, advocates may successfully lobby state government departments for access to individualised funding for personal care so that a young person can attend school, where the person's own efforts to make their case to various departments have failed.<sup>56</sup>

Systems advocacy is crucial to ensure that legislation, policies and practices adhere to international conventions, and the National Disability Strategy. Systems advocacy also informs and educates systems, services and the community about all those important measure, but also embeds values and vision for a civil society. <sup>57</sup>

Systemic advocacy helps by making recommendations on appropriate reforms to relevant bodies.<sup>58</sup>

Disability Advocacy Network Australia Response to NDAP Review 2016

<sup>&</sup>lt;sup>53</sup> *Models of Disability Advocacy,* Department of Social Services Website.

<sup>&</sup>lt;sup>54</sup> (Recommendation 21.1, Access to Justice Arrangements Inquiry Report)

<sup>&</sup>lt;sup>55</sup> Family member of a person with disability, NSW.

<sup>&</sup>lt;sup>56</sup> Disability advocate, VIC.

<sup>&</sup>lt;sup>57</sup> Family member of a person with disability and disability advocate, QLD.

<sup>&</sup>lt;sup>58</sup> Disability advocate, QLD.