

# The Review of the National Disability Advocacy Program



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## Introduction

### Review of the National Disability Advocacy Program

Communication Rights Australia ("Communication Rights") is a human rights information and advocacy organisation which works in partnership with people who have communication difficulties. People request our service when they experience discrimination, isolation or exclusion.

Communication Rights represent a range of people on a continuum from severe speech and communication difficulties (such as Autism Spectrum Disorder, acquired brain injury), illness (such as Motor Neurone Disease, stroke, mental health, physical and sensory impairment, intellectual disability), through to children whose capacity to communicate impacts on correctly and consistently sending their message (such as Apraxia). People approach Communication Rights when their ability to communicate their message is impacting on their ability to access their human rights.

Communication Rights uses the United Nations Convention on the Rights of People with Disabilities ("UNCRPD"), Victorian Charter of Human Rights and Responsibilities Act ("The Charter"), disability discrimination legislation and government policies to ensure people can enjoy their rights. Their activities promote change and facilitate inclusion into community activities.

The Disability Discrimination Legal Service (DDLS) is a community legal centre that specialises in disability discrimination legal matters. DDLS provides free legal advice in several areas including information, referral, advice, casework assistance, community legal education, and policy and law reform. The long term goals of the DDLS include the elimination of discrimination on the basis of disability, equal treatment before the law for people with a disability, and to generally promote equality for those with a disability.

Communication Rights and the DDLS have a Memorandum of Understanding and work together in partnership with reciprocal referrals and support. Given the overlapping of general and legal advocacy, this approach has benefited clients greatly.

Leadership Plus is a disability advocacy service, funded by the National Disability Advocacy Program. Using a human rights framework based on the UNCRPD and The Charter our advocacy work seeks meaningful outcomes for people with disability. Leadership Plus prioritises people living with acquired brain injury and is a state wide service. In the Victorian Local Government Areas of Dandenong, Kingston and Casey our advocacy work prioritises people from a CALD background.

Leadership Plus, Communication Rights and DDLS are all member agencies of the peak organisation, Disability Advocacy Victoria and are represented on the board. Disability Advocacy Victoria also worked with the Victorian Council of Social Services to prepare a submission to this review.

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?

1.1.1 There is no evidence that the model of advocacy impacts on the quality of service delivery, as long as the service is operating from clear guiding principles based on human rights, and is appropriately resourced.

All models of advocacy should start from the same premise – equity of access and protection of individual human rights. Whether it is citizen, family, systemic, legal or individual, the focus should be on the rights of the individual and the barriers to them being fully included in the community. Organisations choose their model of advocacy based on their communities’ needs and funding requirements. While the notion of one organisation providing the full range of models may be confusing for some individuals requesting the service, organisations routinely use their working individual efficacy to inform systemic advocacy.

1.1.2 Evidence from previous DSS reviews confirms that the lack of appropriate resourcing impacts directly on the ability of advocates to respond appropriately to the needs of individuals requesting advocacy. There are 58 funded agencies under NDAP, 12,000 individuals receive direct advocacy services across Australia yet there are 4 million people with disabilities<sup>1</sup>. This represents a significant unmet need.

Communication Rights Australia provides human rights advocacy across the state of Victoria. They are funded for one advocate for a potential 250,000 people with speech difficulties. Its advocacy service, because of inadequate funding, is set up to fail its brief - protecting the rights of one of the most marginalised and isolated communities. Advocacy is provided to address both real and threatened infringements of a person’s human rights. Our criterion for access is that the person is unable to speak up for themselves or is being ignored because they do not have a means to communicate. Not being able to speak up and complain or ask for help further marginalises our community members. The majority of people who need advocacy never receive it because they cannot reach a trained advocate.

In providing human rights advocacy, the work of an advocate is part of the broader movement which seeks to change the way people with disabilities are viewed and treated by broader society. This leads into Communication Rights Australia’s systemic advocacy work, unfunded, but still necessary.

In terms of legal advocacy, the Disability Discrimination Legal Service is funded for 2.8 positions to support people with disabilities throughout the State of Victoria in relation to discrimination information and representation. Again, a service hampered by its funding, but valued by people with disabilities due to its specialised knowledge.

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<sup>1</sup> Australian Bureau of Statistics 2009

1.1.3 Unrealistic geographic coverage without any corresponding resources also impacts on quality of service. Technology can be used to reach some isolated communities. Communication Rights and DDLS can provide secondary consultation by connecting with local advocates to work on communication access/advocacy issues. This has been a very successful practice that allows access to our specialist services to other professional services, although a funded Outreach Program would be more responsive to the needs of people with disabilities due to the fact that many do not have access to such technology.

Leadership Plus struggles to meet the service demand and see the need for an adequately funded Outreach Program. While technology can go some way to provide access there are significant numbers of people with disability who require individualised advocacy assistance, face to face.

1.1.4 Those who already access advocacy are some of the most empowered members within the disability community. For many of those with profound disabilities, such as complex communication needs or severe physical disabilities, access to advocacy and safeguards are almost impossible unless strategies are established to actively engage them. An Outreach Service is essential to connect with such groups. Local Area Coordinators, funded under NDIA, will not have the time/resources/capacity to engage fully with people who have complex communication needs/severe disabilities to identify concerns and respond to those needs. We are already finding people having their NDIA plans developed with no consideration to a means to communicate for the individual. They are not able to fully participate in the planning process. A person's environment must also be trained in communicating with an individual and this also goes unfunded.

1.1.5 To ensure equity of access to advocacy for all, advocates should have the skill and knowledge to work with the people they represent and be funded at an appropriate level which allows them to respond. Communication Rights' advocate regularly meets with people who have no functional means to communicate. The first step for the advocate is to obtain a 'means to communicate' for the individual so that they can then request support. It is unacceptable that people are still denied a means to communicate, and that it is not seen as a priority by people within their environment.

It takes time to advocate on behalf of someone who uses alternative and augmentative forms of communication as the process is much slower than speech. Working with clients who, for example, are deaf/blind, also requires time and great expense for relay interpreters. For people with acquired brain injury, there is memory, conceptual and behavioural difficulties. These challenges need to be considered when resourcing an advocacy service. Equally many people cannot use telephones and require face-to-face meetings; hence an outreach service is essential.

Referrals for legal advocacy when clients cannot give instructions due to not having a means to communicate, is almost impossible.

## 1.2 What are the draw backs?

1.2.1 There are no draw backs to a human rights model of advocacy. It is inappropriate to restrict the models of support funded through NDAP as a 'one size fits all' solution as it will not meet the varying advocacy needs of the disability community.

A robust advocacy sector that is appropriately funded will quickly impact on the marginalised and vulnerable community members by:

- decreasing long waiting lists;
- enabling access to justice for abused individuals;
- preventing severe behaviours of concern continuing or escalating, thereby minimising restrictive practices and community access breakdowns;
- ensure individuals with a means to communicate are provided with the supports they need to do so;
- better targeting resources through an agreed data collection process that identifies gaps;
- Reducing the need for situations to become legal complaints due to a lack of resolution at the first level.

1.2.2 Access to legal services is a major concern as local generalist Community Legal Centres s are often not sufficiently skilled to work with the people who have diverse disabilities. The practice framework of some lawyers relies on their clients to be responsive and provide them with timely and detailed instructions. It is not viable to work with all people with disabilities in this fashion. Many lawyers who do not have an understanding of disability make the same discriminatory assumptions that the rest of the community do. Hence, people with disabilities who decide to use legal advocacy as a means of obtaining an outcome will often need then nonlegal advocate to facilitate that process, again, requiring further resources. While this is not so much of an issue for disability specialist community legal centres, it is an issue for the general legal community.

## 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?

1.3.1 Allocation of funding for peak bodies, both state and national, to harmonise the various models of advocacy would enhance advocacy services. The peak bodies would enhance professional development for advocates/organisations and complement the end goal of equity of access to advocacy regardless of location. Peak bodies allow sector wide projects with the aim of improving advocacy services, such as developing mutually understood measurable outcomes, referral protocols and so on.

There is no framework for shared planning or development for advocacy services between the jurisdictions across Australia.

1.3.2 Allowance for networking and planning within the funding model would provide opportunities to develop a more streamlined approach to advocacy. It is in the interest of people with disabilities for advocates to have an efficient and accessible system.

13.3 Individuals requesting advocacy will decide on the 'practice models used by advocacy services' that best suits their needs.

1.3.4 Specialist agencies have proven means to connect with their communities that have been developed over a long history of involvement. The longevity of connection with their community is essential to be able to respond to the wide variety of needs. Communication Rights receives referrals from service provision, governments, families, community groups, including other advocacy groups, and self-advocates with them having the knowledge that the practice model and skills/expertise of the advocate best suits the needs of the person requesting the service.

Communication Rights and DDLS use a number of options for people to contact the agency which includes:

- 1300 line;
- National Relay Service;
- Face-to-face;
- On-line platform;
- Secondary consultation;
- Unfunded/funded outreach to link into marginalised people.

Our advocacy services are designed to enable people with a disability to increase control over their lives through the representation of their interests and views.

1.3.5 Funding of advocacy agencies is variable, and funding for many smaller agencies is insufficient to meet the full costs of running their service, compromising their ability to provide effective services. It is apparent that funding from the Australian government and state and territory governments does not match the population distribution of people with disabilities.

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?

2.1.1 Specialist advocacy agencies have the skills and expertise to respond to the needs of the community they represent (including all those groups above). Strong partnerships between specialised advocacy agencies overcome these barriers, however the time and effort to put into meaningful partnerships where training and knowledge is regularly exchanged, requires resources. Within the specialist agencies research/knowledge/expertise has been developed over many years of working and engaging with their community. Further, strong networks have been established with professionals and service providers to ensure easier access for isolated clients or for those who are in crisis (abused). Many of the groups mentioned above do not access generalist advocacy services because they are reliant on the knowledge base built up by specialist agencies to facilitate their voice to be heard effectively and efficiently. Generalist advocacy services do not always have the relevant skills.

2.1.2 For many of the groups above, the specialist knowledge of the advocate supports the individual to have a voice in the type of service they receive, capacity to complain and to take action when required. For many people who have been disadvantaged/disempowered engagement with an advocate is a delicate process that needs to be nurtured, this specialist knowledge assists with this process. For the disempowered members of the community, who have never accessed advocacy, a bridge needs to be built to the individual (Outreach Program) so they have the support/confidence to safeguard their rights. Individuals need to build trust in an advocate to be able to share potentially confidential information with them.

2.1.3 Advocacy services need to have the knowledge and expertise to work sensitively with these communities and provide the referrals to key professional services when necessary. Many of these services may need to be accessed prior to advocacy being commenced so as to remove the individual out of a crisis situation for example: Police, Functional Behaviour Expert, or Augmentative and Alternative Communication Speech Pathologist.

2.1.4 Increased funds for interpreting services. In order not to breach discrimination legislation legal and nonlegal advocacy services must have unlimited access to interpreters at all times, for all facets of their services. Currently, disability community legal centres have a cap, meaning that when the cap is reached, in theory, further access for people who are deaf, deaf/blind, or have a disability and are from another country, is not able to be provided,

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

'One model fits all' approach to advocacy does not work for people who have multi layers of complexity within their lives. Some people may require advocacy but have

no means to communicate and express their concerns. In addition their means to communicate may be symbolic only, and require a number of carefully formulated questions to elicit a helpful response. Engagement can be time consuming requiring a targeted response for some communities.

A similar example could apply to people with Autism Spectrum Disorder, or Acquired Brain Injury. It is only by working with such groups for an extended period of time, constantly acquiring knowledge about the disability itself and the impacts of the disability, that advocates are able to optimally assist people with disabilities and meet their individual needs.

Minimum effective work practice skills include the following:

- Practice framework that has been trialled and refined to meet the needs of the individual requesting advocacy;
- Practice framework based on human rights and best practice;
- Learning the individual's method of communication so that clear message sending can be achieved;
- Allocation of an appropriate amount of time to engage with the individual;
- Knowledge base of how the disability is impacting on the individual so that they can be supported to achieve their goals;
- Good understanding of human rights instruments and government policies and procedures to assist in leveraging for change when required;
- Understanding of barriers faced by individuals and how to resolve them;
- Access to professional staff to assist in bringing the change the individual requires;
- Good data collection and reflective practices to ensure evaluation occurs with the objective to improve outcomes for individuals;
- Secondary consultation model of advocacy which provides local advocacy services with knowledge to respond to individuals with complex communication needs;
- Agreed referral process where expectations are clearly articulated and agreed;
- An outreach and information program linked to advocacy;
- Block funding.

What does not work well:

- Under-resourced advocacy service;
- Advocates who have no understanding of human rights, barriers faced by individuals and how to engage each individual with a disability fully;
- Advocates who sit in an office;
- Advocates who make assumptions about what clients want;
- Individuals funding their own advocacy;



- The commoditisation of people.

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

Under the Commonwealth State Territory Disability Agreement (CSTDA), advocacy is an area of joint responsibility for the Commonwealth, State and Territory governments. As in several other areas of the CSTDA, the coordination of services between the jurisdictions seems to be problematic.

A consistent funded data collection process that reports to an independent body which in turn reports directly to parliament should be established across the sector. It should be in the interest of government to understand how their policies are being implemented, how effective they are, and areas of concern for future policy direction.

The establishment of a new national body to receive and oversee complaints, including complaints of abuse against people with disabilities has been widely discussed as a result of the federal Senate Community Affairs References Committee<sup>2</sup> inquiry into the abuse of people with disabilities and a similar report recently released by the Victorian Family and Community Development Committee<sup>3</sup>. Funded peak bodies for the advocacy sector could oversee the establishment of a data collection system that addresses general advocacy issues. Currently the myriad of data collection systems that are required due to differences in funding does not allow advocacy agencies or government to obtain a consistent understanding of the issues people with disabilities face and require advocacy for.

Coordination of data from the NDAP needs to also feed in to the systemic issues that will be raised through the NDIS. Where Local Area Coordinators will identify systemic issues and feed into the Disability Taskforce.

### 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

<sup>2</sup>[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Violence\\_abuse\\_neglect](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect)

<sup>3</sup><http://www.parliament.vic.gov.au/fcdc/inquiries/article/1851>

- state disability advocacy organisations
- peak bodies?

On the whole advocacy groups do work with the above mentioned organisations. Within Victoria we have a state peak body, Disability Advocacy Victoria, that has a membership consisting of independent advocacy organisations and associated members. The latter group consists of organisations such as the Office of the Public Advocate and the Office of the Disability Services Commissioner, who have an interest in independent advocacy but do not operate as an independent body. The full membership consists of approximately half of the organisations funded both by state and federal groups. Some funded advocacy groups are not eligible because they are not independent of disability support service provision.

Most independent advocacy groups commonly use such bodies as AHRC, Ombudsman's organisations and VEOHRC as part of their process for escalating advocacy cases.

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

Communication Rights has a pro-bono legal service establishing some recommendations for them to consider how best to manage this issue. It may be that the advice will be that if an organisation wants to provide services and provide advocacy, what is required is a completely differently branded organisation with different contact details to ensure no perceived or actual conflict of interest exists. It might remain under the umbrella of the parent organisation so tax benefits are not lost and surplus reinvested into advocacy.

The organisation might need to adopt policies and procedures that screen the service provider from any details of the advocacy cases. This separation of service provision and internal framework would ensure compliance of any conflict of interest or ethical considerations. It may be that an individual cannot receive advocacy and services from the same organisation. Informational sharing of confidential material should be part of the existing advocacy procedures that should be sufficient to comply with perceived and actual conflicts.

Structures used in legal offices are:

1. Limiting internally, access to documents, files, computers and other sources that hold information about separate areas of the business.
2. Physically separating areas of work.
3. Strong conflict of interest procedures and checks.

4. Having new employees complete a questionnaire concerning their former associations and involvements.

5. Notifying the client about potential conflicts.

The steps above should address most potential conflicts sufficiently. However, we are mindful that there are a number of different organisational structures that could address these issues more broadly.

For Communication Rights most advocates complete their advocacy visits at the individual's home or at their day placement so there is less chance of clients being confused by shared premises. Legal centres already practice strict conflict of interest methods.

4.2 How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?
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NDAP should fund advocacy independently of NDIS.

NDIS could block fund information, education, capacity building and decision-making supports for individuals through the ILC stream to advocacy agencies. These are 'advocacy like services' and should not be funded through the individual's plan. A person should not be disadvantaged by not having the skills required to make a decision. These types of services should not replace advocacy but enhance it and further strengthen the need for disability services to comply with their human rights obligations. If advocacy is funded through individual plans, for clients with complex communication needs, advocacy service could take a more significant part out of their plan and reduce their access to actual services. A person's disability should not penalise them in terms of access to services, they should not have to make a decision between advocacy and service provision.

No advocacy service should provide service coordination under NDIA without addressing the significant potential for conflict of interest, there is also inherent confusion for clients..

LACs should have an understanding of the available advocacy services to refer people as required.

4.3 What policies and strategies do we need to protect the rights of people with disability?
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Quality policies and strategies that are monitored through accreditation process should provide the safeguards to protect the rights of people with disability. There should be no extra layer of requirement imposed. In terms of protection from abuse, we refer to some of the most recent reports...

### 5.1 What forms of legal review and representation do people with disability need most?

People with disability require at least the same representation as other members of the community, but due to the nature of having a disability also require specialised services. A strong disability discrimination legal service needs to be strengthened so that it can more effectively engage efficiently with advocacy groups in a proactive way, and ensure they can serve the community. Generalist disability specialist legal centres that can specialise in disability issues also need to be strengthened. Clear boundaries between advocacy and legal service needs to be established with protocols concerning sharing of information. Legal services manage their client files very differently from advocacy groups. Their practice is to direct individuals rather than support them to make decisions.

Communication Rights Australia and Disability Discriminations Legal Service have established a partnership to ensure the rights of people with a disability can benefit from a streamlined process to access legal advice/advocacy in the area of discrimination and human rights. This has been very success partnership both for the legal and advocacy service with both organisations bringing their strengths to the table and complementing each other. Such partnerships are to be encouraged.

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

There have been a number of reports on access to justice for people with disabilities, and for disadvantaged people generally. We refer to the Australian Human Rights Commission Report “Access to Justice in the Criminal Justice System for People with Disability”<sup>4</sup> and the Productivity Commission’s ‘Access to Justice’<sup>5</sup>. These reports and their recommendations are still relevant.

To summarise however, when access to justice is considered, education is the first requirement. People with disabilities must firstly understand their rights, before they can press them. Community legal education in relation to discrimination in the area of service provision, appeals under administration law, guardianship and other disability specific areas of law needs to occur constantly and ensuring that the most marginalised receive this education. This is currently unlikely due to the resources provided to disability specific community legal centres.

After education, disability specific legal centres must have the capacity to respond for specific information and advice regarding an individual’s circumstances. They must be resources not only to ensure they have sufficient staff into provide equitable service, but also to hire language, Auslan/deaf blind interpreters and Communication Support Workers when required.

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<sup>4</sup> <https://www.humanrights.gov.au/our-work/disability-rights/projects/access-justice-criminal-justice-system-people-disability>

<sup>5</sup> <http://www.pc.gov.au/inquiries/completed/access-justice>

Lastly, but most importantly for some, legal services must have the ability to be in attendance at mediation, at conciliation and then run court cases when required. These services are intensive and must be funded. This funding should cover independent communication support workers.

Courts and tribunals must also ensure they are accessible to all people with disabilities. This is beyond our control and lies with government.

The Australian Human Rights Commission in its “Access to Justice in the Criminal Justice System for People with Disability” Report identified 5 key barriers to accessing justice for people with disabilities:

**BARRIER 1.** Community support, programs and assistance to prevent violence and disadvantage and address a range of health and social risk factors may not be available to some people with disability. This means that people with disability are left without protection and face ongoing violence, or have repeated contact with the criminal justice system because appropriate programs and community support are not available.

**BARRIER 2.** People with disability do not receive the support, adjustments or aids they need to access protections, to begin or defend criminal matters, or to participate in criminal justice processes.

**BARRIER 3.** Negative attitudes and assumptions about people with disability often result in people with disability being viewed as unreliable, not credible or not capable of giving evidence, making legal decisions or participating in legal proceedings.

**BARRIER 4.** Specialist support, accommodation and programs may not be provided to people with disability when they are considered unable to understand or respond to criminal charges made against them (‘unfit to plead’). Instead, they are often indefinitely detained in prisons or psychiatric facilities without being convicted of a crime. This situation mainly happens to people with intellectual disability, cognitive impairment and people with psychosocial disability.

**BARRIER 5.** Support, adjustments and aids may not be provided to prisoners with disability so that they can meet basic human needs and participate in prison life. They often face inhuman and degrading treatment, torture and harmful prison management practices.

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

We believe that specialist disability Community Legal Centres offer the most effective means in meeting the needs of the disability community.

Community legal centres pride themselves on their connections with their community. Currently, for example, Disability Discrimination Legal Service and Villamanta Disability Rights Legal Service have strong connections with the disability

community, and are on the board of Disability Advocacy Victoria amongst other disability organisations and networks. By having these connections they are well placed in understanding the diversity and need of the disability community which informs their systemic advocacy and strategic planning

Staff have developed expertise over many years of working with people with disabilities and have expert knowledge in the specific legislation that is most commonly required to be used within the community.

Expectations that people with disabilities can easily access general legal centres may be well-meaning but are naively held. It is suggested that people with disabilities be asked for their experiences in attempting to access generalist legal centres and how successful that was.

While specialised disability community legal centres are funded from different State and Federal departments, to ensure a coordinated and planned response, these departments must communicate to ensure that responsibility for a strong disability specialist community legal sector is held by all those involved.

#### **Recommendations:**

1. Access to advocacy and safeguards are almost impossible unless strategies are established to actively engage people with disability. Outreach is crucial.
2. A framework is needed for shared planning and development for advocacy services between the jurisdictions across Australia.
3. Specialist agencies have proven means to connect with their communities that have been developed over a long history of involvement. A continued commitment to specialist agencies is essential.
4. Increased funds for interpreting services and communication support are needed in order to comply with discrimination legislation. Legal and non-legal advocacy services must have access to interpreters and communication support workers at all times, for all facets of their services.
5. A consistent funded data collection process that reports to an independent body which in turn reports directly to Federal Parliament should be established across the sector.
6. Funded peak bodies for the advocacy sector could oversee the establishment of a data collection system that addresses general advocacy issues.
7. NDAP should fund advocacy independently of NDIS.
8. Clear boundaries between advocacy and legal services need to be established with protocols concerning sharing of information. Legal services manage their client files very differently from advocacy groups. Legal practice is to direct individuals rather than support them to make decisions.
9. Legal services must have the ability to be in attendance at mediation, at conciliation and then run court cases when required. These services are intensive and must be funded.