Council for
Intellectual Disability

SUBMISSION TO NSW DISABILITY ADVOCACY REVIEW

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Introduction to CID and our role in advocacy and information

NSW Council for Intellectual Disability (CID) is a disability rights organisation led by people with intellectual disability. For more than 60 years, we have been working to ensure a community where all people with intellectual disability are valued.

Until recent years, CID's activities were largely confined to systemic advocacy and information provision on behalf of a membership mainly made up of people with intellectual disability and their families.

CID currently receives from the NDIA ILC program substantial funding for information and capacity building projects. This funding is time limited project funding.

The core role of CID continues to be systemic advocacy as a disability representative organisation.

The majority of the board of CID must be people with intellectual disability and, since 2002, all of our chairpeople have been people with intellectual disability.

In 2018, CID's systemic advocacy and representation was very positively evaluated by Professor Christine Bigby and Dr David Henderson from La Trobe University. See the Appendix to this submission for some key findings of this evaluation and a link to it.

How is CID's disability advocacy and information work currently funded?

CID's disability advocacy work is wholly funded by the NSW Government.

CID's information service was funded by the NSW Government for many decades until 2018. We then received a two year grant from the NDIA (ILC) to maintain and extend the information service but that grant expires in June 2020. We were unsuccessful in seeking continued funding for this service.

The meaning of advocacy

We do not seek in this submission to define disability advocacy. However we do draw the Commissioner's attention to the important work of Errol Cocks and Gordon Duffy who wrote for the Commonwealth government the monograph, The Nature and Purposes of Advocacy for People with Disabilities 1993. Professor Cocks also considered the definition and key aspects of disability advocacy in an introduction to Intellectual Disability in Australia 3rd edition Australian Institute on Intellectual Disability 1998. There, Cocks summarised that the key assumptions and principles that underpin advocacy include:

- Advocacy is on the side of a disadvantaged person or group (as opposed to human services which are answerable to many different stakeholders).
- Advocacy is concerned with genuine life needs with a focus on the major and most urgent needs of vulnerable people.
- Advocacy minimises conflicts of interest with this principle highlighting the difficulty of human service providers in putting aside their own interests and acting solely in the interests of people with disability.
- Advocacy needs vigour and energy in order to be effective.
- Advocacy has fidelity to a disadvantaged person with a focus on carrying out commitments made to people.

As emphasised by the Disability Advocacy Alliance submission, advocacy must be genuinely independent and avoid actual and perceived conflicts of interest.

In particular, advocacy organisations need to be independent from core disability support services. In our view this includes independence from support coordination. Advocacy is often needed because support coordination is inadequate. Funding in plans for support coordination is often inadequate so that providers of it either provide inadequate coordination or have to cross subsidise it.

A vast undersupply of advocacy

The need for advocacy has always been vastly less than the supply. Individual advocacy groups could provide information on priority systems and other data on how they cannot meet the needs that people come to them with.

As a systemic advocacy organisation, CID has to tightly prioritise the competing needs we can address through our systemic advocacy. For example, some of the important issues that we are currently unable to address include:

- Corrective Services and Juvenile Justice - The abuse and often inadequate support experienced by people with intellectual disability in gaols, community corrections and juvenile justice.
- TAFE - Inadequate access to further education in the TAFE system and private colleges.
- Child protection and out of home care – Challenges facing children and young people with intellectual disability who have been removed from their parents or are at risk of removal.

- Public and community housing – Inadequate supply and inappropriate housing provided to people with intellectual disability.

Also, where we can address an issue, we need to tightly prioritise which aspects we address. For example, health of people with intellectual disability is one of our top priority advocacy issues and we have made some substantial gains in establishment of specialist intellectual disability health services to backup the mainstream and recently in the development of a national roadmap for action However, we have not been able to include or maintain a direct focus on some key issues such as the capacity of hospitals, community health, drug services and public dental services to provide adequate access and reasonable adjustments for people with intellectual disability.

Factors impacting on the level of need for advocacy in NSW

The NDIS is a rights-based system allowing people with disability and major functional impairments to access "reasonable and necessary" supports. Paradoxically this has increased rather than decreased the level of need for advocacy which is now higher than it was prior to the introduction of the NDIS:

- Experience has shown that advocacy is often essential to get access to the NDIS, get a reasonable funding package and then to deal with service providers including support coordinators. This is due to intricate NDIS processes, inefficient and inconsistent application of these and a very inadequate supply of quality services. As Malbon, Carey and Meltzer (2019) concluded, personalisation schemes like the NDIS "put unprecedented emphasis on individuals to advocate for their own rights and navigate burdensome administrative systems". (Personalisation schemes in social care: are they growing social and health inequalities? https://academia.edu/resource/work/39687532)
- Only 10% of people with disability are eligible for NDIS packages.
- There is continuing need for advocacy with mainstream state and federal government and private services and this need has been increased by the NDIA taking a narrower view of its role than had previously been taken by the NSW government disability services. For example, it was only after a lengthy campaign led by CID and extensive negotiations between the states and the Commonwealth that the NDIA accepted responsibility for life and health preserving swallowing therapy needed by many people with disability.
- The responsibility of the State government to ensure protection of the rights of people with disability and support by mainstream services has been considerably increased by the Disability Inclusion Act, the National Disability Strategy and the United Nations Convention on the Rights of People with Disability.
- The Disability Royal Commission is raising the profile of rights infringements experienced by people with disability leading to an increased expectation on advocacy to respond.

Benefits flowing from advocacy

A vibrant advocacy sector leads to many benefits for both people with disability and government.

Benefits to people with intellectual disability that flow from CID's systemic advocacy include:

- Enhanced voice for people with intellectual disability in public debate and in relation to government decisions that affect them.
- Enhanced access to the disability support services that people with intellectual disability want and need.
- Enhanced access to mainstream services and those services better reflecting people's wants and needs.
- More valued and included lives in the community.
- Better protection of people's rights to be free from abuse, neglect, exploitation.
- Better awareness in the wider community of the on-going discrimination and violation of rights that people with intellectual disability face.

Benefits that flow to the NSW Government include:

- The capacity to obtain informed input to policy and service development from the ID community. CID is currently represented on 11 NSW advisory committees and receives numerous other requests for advice to government bodies.
- Assistance and guidance in delivering on the State's obligations under the Disability Inclusion Act and National Disability Strategy.
- Protection of the NSW investment in the NDIS by it being more responsive to wants and needs of people with intellectual disability.
- Early warning when Government and community services are not working for people with intellectual disability.
- Cost savings through earlier and better integrated responses to the needs of people with intellectual disability avoiding problems becoming more entrenched and more costly to address.
- Cost savings to the State through enhanced NDIS and other national responses leading to savings in State budgets such as justice and health.
- Improved understanding and commitment from civil society to working towards full inclusion.

State-based systemic advocacy organisations are needed as well as national ones

There are many issues that are particular to each State, in particular issues with State agencies such as Health, Education, Transport and Justice. Only State based systemic advocates have the local groundings in their communities and the local knowledge and networks to be able to address these.

There has never been any suggestion that the Australian Government will fund State-based systemic advocacy.

People with intellectual disability need their own State peak/representative organisation/systemic advocate

This is so because:

- People with intellectual disability have particular needs which are often different to people with other disabilities, for example consideration of cognitive access to services as compared with the much more high profile physical and sensory access.
- Consistent with the CRPD, people with intellectual disability should be supported to lead a representative organisation and take part in public debate and government decision making that affects them. It is very difficult to provide these leadership opportunities in a cross disability organisation. CID does this by a range of strategies including:
    - the majority of its board having to be people with intellectual disability,
    - support for board members to exercise their roles,
    - adjustment of board and other leadership processes to be accessible and inclusive of people with intellectual disability,
    - training and support of people with intellectual disability to represent CID on government advisory bodies, in meetings with ministers and senior bureaucrats, in public forums and many other similar capacities.

Systemic advocacy characteristics

CID’s systemic advocacy has the following characteristics:

- Clarity of purpose based on achieving changes in governmental and other service systems, the community and laws.
- Leadership by people with disability with support as needed to develop and support leadership/systemic advocacy skills.
- Secondary leadership by family members.
- Being grounded in the life experience of people with disability, and in research evidence.
- Based on a clear definition of a problem and practical solutions to that problem.
- Considered strategies for achieving reform.
- Collaborative with wide-ranging allies.

- Assertive and persistent but also building working relationships with decision-makers.

Outcome measures for systemic advocacy

We agree that advocacy organisations should be accountable for the outcomes that they achieve. We see the existing accountability mechanisms of the National Disability Advocacy Program and the Victorian Government's disability advocacy program as inadequate in that they are much more focused on outputs rather than outcomes. However, an outcome system needs to be designed with great care to avoid any disincentive against advocacy services addressing the hardest problems of individuals and the most challenging systemic problems. It also needs to be recognised that advocacy is often a long haul with clear positive changes for people with disability only occurring after many years.

The following are possible outcome measures for systemic advocacy:

- Based in the life experience of people with disability and their families.
- Based in research.
- People with disability taking a leading role in the advocacy with the development and support to enable this.
- Alliances formed with other stakeholders and eminent individuals and organisations.
- Access to key decision makers.
- Invitations onto government advisory bodies.
- Specific invitations to provide comment on proposed government initiatives.
- Commitments and actions by decision makers in line with our advocacy.
- Social media numbers including followers, likes, shares.

All outcomes, and outcome measures need to be developed in consultation with disability advocacy organisations.

Capabilities needed for systemic advocacy

We see high quality systemic advocacy as requiring capabilities such as the capacity to:

- Engage with and support people with disability and family members to take leading roles in systemic advocacy.
- Gather relevant research evidence and experiences of people with disability.
- Analyse government policies and priorities so as to see opportunities for, and barriers to, reform.
- Consult and collaborate with potential allies including in the advocacy and research sectors.
- Formulate reform proposals that are evidence based.
- Develop working relationships with key decision makers.
- Argue a case persuasively.
- Develop strategies to gain support from decision makers.
- Develop and run broad based campaigns.
- Engage proactively with the media.

- Regularly reflect on and change strategies.

Informants of systemic advocacy

If an organisation does individual as well as systemic advocacy, the individual advocacy will be one of the valuable informants of the organisation's systemic advocacy. However, the experience of individual advocacy is only one of various informants of systemic advocacy. At CID for example, our systemic advocacy is informed by a range of sources including the experiences of people with intellectual disability and their families and other allies involved with CID, the direction of our board, advice from our Advocacy Group of people with intellectual disability, issues raised with our information service, issues coming out of our ILC projects, research evidence, consultation with other advocacy organisations and professional bodies and issues highlighted by people with disability and their allies on social media

CID would welcome funding to carry out individual advocacy as well as systemic advocacy. However, we do not see this as in any way necessary to enable us to provide well informed systemic advocacy.

If an organisation is funded for both individual and systemic advocacy, there should be separate funding allocations for each. If an organisation receives one amount for both individual and systemic advocacy, it can be very difficult indeed to avoid the striking here and now needs of individuals leading to most of the organisation's efforts being focused on individual advocacy.

We also emphasise the valuable way in which different advocacy organisations can complement each others' work. For example, CID and the Intellectual Disability Rights Service have complementary roles that inform each other. IDRS is a vital source of individual legal advocacy for people with intellectual disability and its experience and legal expertise informs CID's systemic advocacy.

A systemic advocacy case study – specialised intellectual disability health services to back up mainstream services

The below case study illustrates many aspects of successful systemic advocacy including that it tends to be a long term process with regular revisiting of short term goals and strategy.

In 2001, CID decided to place a major advocacy focus on the health inequalities experienced by people with intellectual disability. We took this decision and grounded our thinking on the basis of the stories that people with intellectual disability and their families told us about their struggles with the health system and the developing research evidence showing health inequalities. This included a landmark study showing that over 40% of health conditions went undiagnosed and untreated for people with intellectual disability. People were dying much earlier than the general population.

We began by collaborating with the then Community Services Commission to run a conference to draw out and highlight key issues and potential solutions.

From quite early on, we saw two reforms as needed. The whole mainstream health system needed to lift its capacity to respond appropriately to people with intellectual disability.

Also, there was a need for a statewide network of specialised intellectual disability health services to backup the mainstream.

We pressed the need for action with the Minister for Health who was supportive. The Department of Health responded by funding the development of training programs, policies and resources for hospital staff and GPs.

Meanwhile, we built community, professional and bureaucratic support for our advocacy for specialist services to backup and drive change in the mainstream. This included preparing a detailed proposal backed by case studies illustrating the personal cost to people and the financial cost to government of allowing health conditions to go undiagnosed until they became chronic or acute.

In 2006, our persistent advocacy struck a responsive chord with the relevant middle manager in the Department of Health. With support from her, we organised a State roundtable on the health of people with intellectual disability. Participants included a person with intellectual disability and family members talking about their problems with the health system, intellectual disability health professionals and researchers, leaders in the health and disability bureaucracies and President of the College of General Practitioners. The Deputy Director General of Health attended and later that day we met with him and the Director-General. They agreed that the Department needed to act and initiated the development of the Service Framework to Improve Health Care of People With Intellectual Disability which was a three-way partnership between the Department of Health, the Department of Ageing, Disability and Homecare and CID.

The Framework spelt out the broad reform that was needed across the health system including the need for specialised services.

We campaigned for action on the Framework and in the 2010 State budget, money was provided for piloting of a specialised intellectual disability health service and establishment of an Intellectual Disability Network in the Agency for Clinical Innovation.

As well as targeting the then Labor Minister, we had an ongoing relationship with the Shadow Liberal Health Minister. When government changed in 2011, she funded two further specialised health services in the next budget.

These services (in three out of fifteen Local Health Districts) were pilots to be evaluated over four years and we continued to be active in the committee that oversaw the pilots and evaluation.

While the evaluation of the pilot services was positive, there was no indication that funding would follow for further services.

We had been a partner in a major data linkage project led by Professor Julian Trollor which was providing a much stronger research base for the health inequalities facing people with intellectual disability. Key findings of that study were released in February 2018 showing that 38% of deaths of NSW people with intellectual disability were potentially avoidable. There was considerable media focus on this study assisted by a case study we had initiated of a mother whose daughter had died a tragically avoidable death when she was turned away from a local hospital.

We commenced the Deadly Disability Discrimination campaign which focused on funding of a full statewide network of intellectual disability health services.
https://cid.org.au/our-campaigns/end-deadly-disability-discrimination/

We gained very broad support for the campaign including a petition supported by 11,271 people and an open letter signed by 56 eminent people. At the same time, we were working with senior bureaucrats and a health minister who showed a clear understanding of the issues.

In the 2018 budget, funding was provided to extend the pilot intellectual disability health services to a statewide network of six core services with outreach workers in the other Local Health Districts. Funding was also provided for two statewide hubs of expertise in mental health of people with intellectual disability. All these services would both act as specialist consultants for people with complex health needs and provide training and capacity building across the mainstream health services.

After a long and frustrating initial period, we have achieved major gains in access to specialised services when needed by people with intellectual disability. The funding of these services remains limited and we continue to argue that there should be a full specialised service in each Local Health District rather than just in six districts.

We continue to be involved in the advisory committee for the specialised services which will be evaluated. In light of that evaluation, we would expect to be campaigning for further funding enhancements.

Responsibility for funding of information services

Standalone provision of information and referral is the responsibility of the NDIS. However, the availability of information in NSW needs to be maintained until the NDIS establishes an at least equal ongoing availability of information as currently exists in NSW. We are a long way from that point at this stage with ILC grants being project focused.

In CID's case, for many decades, we received State funding for our information service in addition to our systemic advocacy funding. In 2018, we received an ILC grant to maintain and extend our information service and so we did not seek transitional information funding from the NSW Government. However, the ILC grant will finish in June 2020. We now look to the NSW Government to reinstate our previous information funding.

Like advocacy, information services should be free of significant conflict of interest or there may be a tendency to refer people to the organisation’s own services and away from a competitor’s.

Finally, provision of information and referral is an ancillary part of all advocacy and this needs to be reflected in funding.

Who in the NSW government should be responsible for funding and monitoring advocacy?

Any State government agency will have a degree of conflict of interest since it will itself be a potential subject of advocacy action. Ideally, there should be a a body completely independent of government to take on this role. Failing that, the most appropriate existing agency to fund and monitor advocacy would be the Ageing and Disability Commission. It has specific responsibility for advancing the rights of people with disability and is independent from departmental and ministerial direction.

The Commission, an advocacy based advocacy resource unit and/or best practice advocacy organisations should also have the role of promoting capabilities and good practices in advocacy. However, these roles need to be resourced with funding.

APPENDIX – The Bigby and Henderson Review of CID

Professor Christine Bigby and Dr David Henderson , La Trobe University wrote a report on CID's systemic advocacy and the leadership role of people with intellectual disability:

" Raising the voices of people with intellectual disabilities and changing systems: The contribution of NSW Council for Intellectual Disability to social change" 2018. www.latrobe.edu.au/__data/assets/pdf_file/0011/974666/NSW-CID-Raising-Voices-Bigby-Henderson-2018.pdf

The report was based on interviews with leading public officials and researchers.

Key findings included:

- CID's edge results from being deeply grounded in the experience of people with intellectual disabilities.
- CID is exceptional in its inclusion of people with intellectual disability in all aspects of its work.
- Outstanding features of CID include its solution-focused approach and its commitment to working collaboratively.
- CID is particularly adept at linking what is happening to individuals on the ground to broader policy directions.
- CID's strategic and sustained approach to key issues has led to significant and lasting change.