



# Raising the voices of people with intellectual disabilities and changing systems:

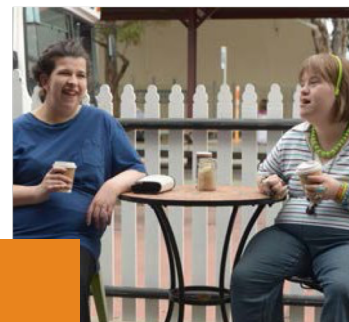
## The contribution of NSW Council for Intellectual Disability to social change

Professor Christine Bigby and Dr David Henderson

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## Contact

Professor Christine Bigby  
Director, Living with Disability Research Centre  
School of Allied Health, La Trobe University, Bundoora 3086  
T 03 9479 1016  
E [c.bigby@latrobe.edu.au](mailto:c.bigby@latrobe.edu.au)



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## Executive Summary

Ensuring the NDIS, mainstream services and the broader community take account of the lived experiences and issues unique to people with intellectual disabilities is a continuing challenge. The NSW Council for Intellectual Disability (CID), has led advocacy in these arenas for many years. Its advocacy service is under threat of closure due to a decision of the NSW Government to stop funding advocacy services. This report summarises a study exploring CID's approach to systemic advocacy, the value of its work, and the costs the loss of this organisation would entail. The findings are based on a document review and interviews with CID personnel and a cross section of senior public officials and academics.

**'No other organisation does what they do as effectively as they do'.** CID is led by people with intellectual disabilities. It is held in high regard and perceived as a credible, strategic, inclusive, agenda-setting organisation. People from all levels of government and service provision are prepared to listen to CID.

**'Gives us a voice in the way of making sure certain people are listening to us'.** CID's central purpose is building the capacity of individuals with intellectual disabilities to find their own voices and undertake advocacy at the system level. Its edge results from being deeply grounded in the experience of people with intellectual disabilities and the planning and execution of its work by leaders with intellectual disabilities, family members and professionals working together.

**Working inclusively, 'they've walked the talk in that regard'.** The inclusion of people with intellectual disabilities in CID is both exemplary and exceptional at all levels of the organisation, from leadership and governance, campaign work, to public and professional education and consultancy. Support for inclusion is ongoing and not left to chance, whatever a person's role or experience.

**'The observer of what's going on, and the translator of that to government'.** The significance of CID's systemic advocacy is in bringing together different parts of the system that impact on the lives of people with intellectual disabilities. CID is particularly adept at linking what is happening to individuals on the ground to broader policy directions. CID drives policy agendas around ensuring access to, and the quality of, the NDIS for people with intellectual disabilities, and also agendas around ensuring easier navigation of the health system and diversion from the criminal justice system. CID is an important source of information and advice for policy makers and bureaucrats. As such, the organisation saves governments and others from having to canvass more widely and synthesise high volumes of information.

**People with intellectual disability are a 'group that misses out'.** There is 'a more powerful need than ever' for CID's systemic advocacy focused on people with intellectual disabilities due to the very specific needs and issues of this group and – in the informants' experiences – the limited visibility of these issues on policy or advocacy agendas. This limited visibility, exemplified in the early design phase of the NDIS, is due to a multi-level system failure to recognise and adjust processes, or to provide the skilled and continuing support, that ensures people with intellectual disabilities can speak out and be heard.

Informants recognised that, in some situations, there is a fine line between issues common to all people with disabilities and those distinctive to people with intellectual disabilities, and noted CID's skills in managing these tensions through ongoing and productive collaborations with other advocacy organisations.

**'Not just putting problems out there but providing an alternative way forward'**. Two outstanding features of CID, in addition to its inclusivity, are its solution-focused approach and its commitment to working collaboratively. These features make CID not only an easy organisation with which to work, but one that is well informed and brings together key allies and stakeholders around particular issues.

**'Key tangible things resulted from their actions'**. CID's strategic and sustained approach to key issues has led to significant and lasting change. Some key achievements are:

- **Criminal Justice** – ADHC (Ageing, Disability and Home Care NSW) policy change to prioritise support for people in trouble with the justice system and establishment of the Community Justice Program, a program which is the envy of other states. This policy change has led to reduced recidivism among people with intellectual disabilities, reduced costs in the justice system, fairer legal processes and better lives. CID did this work in collaboration with the Intellectual Disability Rights Service.
- **Health Services**
  - Specific Medicare items for annual health assessments for people with intellectual disabilities.
  - Establishment of a New South Wales Health framework to improve the health of people with intellectual disabilities, and pilot intellectual disability health teams. This has led to improved health and avoidance of acute conditions becoming chronic.
  - Early indications of better inclusion of people with intellectual disabilities in mental health service planning.
- **NDIS**
  - Putting on the agenda the specific needs of people with intellectual disabilities through the establishment of the Intellectual Disability Reference Group.
  - Influencing the development of the Quality and Safeguarding Framework and NDIS responsiveness to people with complex behaviour support needs.
  - Highlighting the high costs of failing to resolve the demarcation of responsibilities of the NDIS and state government agencies, and also the dangers of the NSW Government losing past gains, particularly around the interface of criminal justice, health and disability services.
- **Changing community expectations** about participation by people with intellectual disabilities, demonstrating it is both possible and how it can be done.
- **Building leadership and capacity of people with intellectual disabilities** – Fundamentally increasing the numbers of people with intellectual disabilities who have

the experience and confidence to act as advisers and educators to government, service providers and academics.

This report captures the outstanding reputation of CID among senior government and service personnel and its contribution to lasting social change for people with intellectual disabilities. This organisation models inclusion of people with intellectual disability in everything it does. CID has driven a NSW state and, to some extent, a national agenda to ensure issues specific to people with intellectual disability are not ignored as they so often have been in the past.

If this organisation were to fold, governments would lose an organisation that has held them to account and also a critical and effective means of involving people with intellectual disabilities in service design. They would therefore lose a key way of understanding whether policy intentions and service design reflected needs on the ground. As one national policy leader said of CID, ‘we need organisations that are ... looking at the big-picture outcomes. We need them’.

## **Raising the voices of people with intellectual disabilities and changing systems: The contribution of NSW Council for Intellectual Disability to social change.**

Two major policies, the National Disability Insurance Scheme (NDIS) and the National Disability Strategy (NDS), are changing the way specialist and mainstream services deliver support to people with intellectual disabilities. As these reforms are implemented, the volume of funding to disability services will double and expectations will rise about the accessibility of mainstream services, such as health, housing, transport and criminal justice. Major issues for people with intellectual disabilities are access to individualised NDIS funding, the adequacy and quality of the market driven supply of support services, the responsiveness of mainstream services to their needs, and the interfaces between disability specific and mainstream services.

Including the perspectives of people with intellectual disabilities in policy reforms and the redesign of service systems is a fundamental premise of most disability policies, the purpose of which, is to ensure their lived experiences and unique issues are taken into account. Despite this, the survival of an organisation that has excelled in supporting the voices of people with intellectual disability to be heard about system level issues is under threat. At a critical time in the reform process, funding for the NSW Council for Intellectual Disability (CID) is endangered as the NSW Government transfers funds previously spent on disability to the Commonwealth.

This report is part of a larger study exploring the rationale for intellectual disability specific advocacy. The study seeks to explore different ways of supporting the leadership and participation of people with intellectual disability in political and civic society, and differences such support can make to individual lives and broader social change. In this report, we summarise our findings about CID's approach to systemic advocacy, the value of its work, and the potentially heavy costs the loss of this organisation would entail.

These findings are based on semi-structured interviews with 11 people who have had sustained contact with CID in their capacity as senior public servants, policy makers, academics, or personnel in disability support or other organisations. In addition, one CID board member with intellectual disability and two CID staff members were interviewed. Organisational documents, such as annual reports, campaign summaries, and transcripts or slides from public presentations were also reviewed. In the interviews, we asked informants

about their experiences of CID and their perspectives on the contribution of CID to engendering social change and improving the lives of people with intellectual disabilities. The data were analysed thematically using a template approach, with initial codes reflecting the key topics covered in the interviews and opportunity for new codes to emerge inductively from the data.

**Reputation and standing: ‘no other organisation does what they do as effectively as they do’**

CID is led by people with intellectual disabilities who must make up at least 8 of its 15 board members. It is a member based organisation and the majority of its 250 members are people with intellectual disabilities. About 50 members are involved in various aspects of the organisation’s work. The organisation has been receiving recurrent funding for its advocacy and related information work, currently \$532,000. It also receives non-recurrent project funding for non-advocacy work. Staff costs are its main expenditure.

The organisation employs the equivalent of twenty full time staff, but the headcount is more, as many work part-time. One core staff member has an intellectual disability and members with intellectual disability are often paid on a casual or part-time basis for the work they do on funded projects.

The organisation has changed significantly since it was founded 60 years ago as a federation of non-government service providers, which were largely parent-run and government funded organisations. By the early 1980s, CID had become a parent-run advocacy organisation and since 2004, it has been an organisation led by people with intellectual disabilities, having taken “the next big leap, to the majority of the board having to be people with intellectual disabilities” [Staff member 1]. The other board members are family members and professionals. The primary foci of CID’s advocacy have shifted from deinstitutionalisation and education in the 1980s and 1990s, to health and criminal justice in the early 2000s, with the addition more recently of NDIS design.

CID is held in high regard by the cross section of senior personnel from the disability arena. Consistently, informants used superlative words such as ‘exemplary’, ‘extraordinary’ and ‘very very effective’ when they talked about this organisation. They drew attention to its credibility, strong values, strategic and clear focus, legitimacy, inclusivity, its agenda-setting role and significance. People from all levels of government and service provision are

prepared to listen to CID – the prerequisite for successful advocacy. Informants said for example:

...if they are raising an issue then there is something of substance. [Senior NSW statutory officer 1]

So, if I got a phone call from CID... I would make time to talk. I get calls from people all the time, and most of them I will just send the email on to someone at NDIS. [National policy leader]

I never got a phone call from CID in any of my roles in any of my contact that I didn't welcome... they're very clear about their purpose, they don't try and pretend that they are anything that they're not - they're very clear about the group and the group of people that they're representing. [Senior federal bureaucrat]

...an ability that few people have in terms of being able to just plain speak what are quite complex issues in a way that isn't threatening for any of the stakeholders particularly government and policy people... [Professor 1]

The standing of CID and its success in bringing about lasting social change is closely associated with its purpose of ensuring leadership by people with intellectual disabilities and its dedicated approach to systemic advocacy. It is a rare type of organisation and its unique features are described in the following sections.

**Purpose: 'gives us a voice in the way of making sure certain people are listening to us'**

Characterising CID is difficult. A very strong part of its purpose is building the capacity of individuals with intellectual disabilities to find their own voices and speak out. Supporting their participation in the organisation's governance and advocacy work are core staff tasks, as one informant said:

CID is the vehicle by which people with intellectual disability have their own voice in public debate and civil society, and that has involved loads of support to people to develop their skills, and that's an ongoing process. [Staff member 1]

Yet CID does not fit the traditional mould of self-advocacy as it has been understood in Australia. It has a wider brief and the work of CID staff extends beyond the role of support workers. CID's purpose sits somewhere between empowering leadership by people with intellectual disability and professional advocacy, and its edge is created by the alliance between leaders with intellectual disabilities, ordinary members and professional staff. Together they work strategically, taking a much stronger systemic advocacy focus than typical self-advocacy groups. They do this by collecting, comparing and picking the pith out of individuals' stories and acting on the wider policy implications these throw up. A board member with intellectual disability captured the unique essence of this organisation as one



that not only supported people with intellectual disability to have a voice, but also made others hear it. He said:

Some people can't speak for themselves, but citizen advocacy and self-advocacy and CID work as a team. We try to get people to do it for themselves... We are trying to get people to have a say for themselves, speaking for themselves. CID gives us a voice in the way of making sure certain people are listening to us. We work together, side by side. We work together with the staff and the board. [CID Board member]

This sense of team work between people with and without intellectual disability, members and paid staff, and the differentiation from self-advocacy was echoed by staff and organisational outsiders who said for example:

The idea works well, because it does have that complement of people without intellectual disability. People who have, and you know not that University degrees make us great people, but skills and experience and knowledge in a broader system. And I think can help, you know. [Staff member 2]

They take on that bigger, broader advocacy around public policy issues, and I think that's really where they stand above some of the other self-advocacy.... I think CID have been able to marry both of those aspects. [Senior service provider]

The working alliance between staff and people with intellectual disabilities means that CID's systemic advocacy is grounded in the experiences of people with intellectual disabilities. The combination of being 'deeply seated at the grassroots' and the planning and execution of its work by self-advocates, family members and professionals working together, makes CID different and its advocacy powerful and credible.

Almost never for example am I dealing with just the staff, and I couldn't say that for most organisations. So that means that I have to think differently, they have to think differently; they have to do things differently, I have to do things differently. So, through its actual actions it changes the way that policy and in my case research is done. [Professor 2]

I think the strong leadership of a number of people with intellectual disability who are part of CID, is important, and very powerful, and those leaders know how to deliver a message in a way which leaves the recipient with a very clear understanding of the importance of responding, and responding appropriately. That is critical, and I think if they did not have a strong reputation of leadership by people with disability, that would be a problem. [Senior NSW statutory officer 1]

### **Working inclusively: 'they've walked the talk in that regard' and 'they don't just pop people in there and just tick the box'**

The inclusivity of CID was perceived as both exemplary and exceptional. A culture of dynamic and respectful support enables the inclusion of people with intellectual disabilities in all parts of the organisation. As one informant remarked 'values and inclusivity are embedded in everything they do'. In CID inclusion takes many forms; leadership and

governance through membership of the board; advice to the board through membership of the Speak Out Reach Out group; campaign work through public speaking, meetings with bureaucrats and politicians and membership of reference groups; public and professional education and provision of advice through public speaking, chairing conferences, consultancy to groups and organisations; and paid work on specific projects such as My Choice Matters.

I've never yet seen an advocacy group anywhere in disability that does it quite as well as they do, I might just say...right through to making sure that the people they represent actually have a voice, not just them speaking on behalf of their members, they advocate successfully and support people with intellectual disabilities themselves to find their own voice. [Senior federal bureaucrat]

Numerous examples were given of inclusion. Powerful public speeches by CID's leaders at places as different as the United Nations, where Robert Strike was one of only 3 people with intellectual disability among 1400 delegates, the opening speech at a conference on abuse organised by the NSW Ombudsman, and a tour of service providers across NSW sharing personal experiences of institutionalisation.

We go out and give talks and talk to different organisations, like the UN. Like, I talked about easy read...I think it has a big impact because [a person with an intellectual disability who's been chair of CID and speaking at that big conference]. They didn't think we could do it. We have to show people that we can do it as well as anybody else, and we need to show people, hey, I'm no different than Jim or anybody else. [CID board member]

Michael Sullivan's opening address makes it clear that it's the impact [of abuse] on members of our community and that's a much more powerful presentation and sends a much more powerful message, and that has assisted us greatly both in terms of the work we continue to do in terms of giving effect to the need to give effect to zero tolerance within disability accommodation environments, but also the government – Work of CID and the leaders of CID involving people with intellectual disability, in my opinion, that's much more powerful than anything I might deliver [Senior NSW statutory officer 1].

One staff member talked about a recent meeting with the NSW shadow Minister for Health he had attended with one of the leaders. Another spoke of supporting a member to be on an advisory committee about accessibility on NSW train services. Academics gave further examples of CID members employed as part of research projects, providing one-off consultations to inform their work or talking with students about inclusive research.

Inclusion is not left to chance by CID. Whatever their role or experience, members are supported to participate in a way that suits them, from working out what views they want to express and how, to the practicalities of getting to a meeting. One of the members talked

about the way staff supported board members with intellectual disability, and another staff member about the process of preparing for an education session.

...she listens... It's important – her role is making certain that all of us are having a say besides the people without disabilities... Yeah, we do, and we go over the agenda to see what's happening, and we also pick who is going to be the chairperson for that day. We take it in turns. [CID board member]

It's okay if I do more of the typing or you know, developing the power points or whatever. But just making sure that we're kind of on track from the start with that stuff. What messages, do you want to give to people... and then involving them through that process and in the delivery, because of course, we need to co-deliver with someone with intellectual disability. [Staff member 2]

Organising support, building the capacity and confidence of members, and matching their interests to opportunities to participate is led by the Inclusion Manager. Both she and other informants drew attention to the challenges and time consuming nature of this work. For example, one staff member explained that it might take up to seven hours to support a member to prepare for a meeting, in addition to the time of actually being at the meeting. As such, this staff member explained how she approached this task by ensuring an individual knew the processes, what they wanted to advocate and the 3 key points they wanted to make. Commenting about the training CID had provided to members of the Guardianship Division of the NSW Civil and Administrative Tribunal, a senior NSW bureaucrat elaborated on the same theme when she drew out the incremental work necessary to building up confidence for this sort of work. She said:

Members of CID with an intellectual disability have spoken at training days for the Guardianship Division. And this is because they've been supported to do that by CID. So, CID has done the skill development with them, they've done the public speaking with them, have got them to a stage where they can come and speak to a large group and then take questions. Those are skills that do not just suddenly appear, they are skills that are developed, and CID does that developing. [Senior NSW bureaucrat 2]

CID does not compromise on the necessity for skilled support and the time it takes to enable the participation of people with intellectual disabilities, either for internal governance and leadership work or external advocacy or education work. Sitting fees for meetings, for example, generally do not reflect the level of preparatory work required by a person with intellectual disability and their supporters, but in some organisations are the only avenue for payment of external experts. One academic talked about the impetus CID had given her to change university policies to recognise the real costs of participation.

One informant commented about the relative homogeneity of the member base of CID. Whether this is the case is not entirely clear, but it is something that staff were conscious of and tackled in various ways. The inherent alliance between staff and members was one way of drawing out perspectives beyond an individual's immediate experiences. CID has also drawn on the experiences of families, particularly in respect to issues for people with more severe intellectual disabilities. Just as important was the role the staff played in supporting members to think beyond their own immediate experiences. As one staff member said:

And one thing we do find hard...helping people to think about other people's experience and see things from other people's experience or perspective. I think that's hard for a lot of us to do and I think it can be hard for a lot of people with intellectual disabilities in particular. And so, perhaps yeah, having that kind of I don't know, other stakeholder staff, you know perhaps, to help that...But then for you know, some of our members and it's something we're trying, I guess, encourage and support is sharing other people's experience and you know, that's the broader picture of people intellectual disabilities. [Staff member 1]

**Systemic advocacy: 'the observer of what's going on, and the translator of that to government.'**

The importance of systemic advocacy at this moment in time about issues particularly relevant to people with intellectual disabilities was consistently highlighted by informants. Their reasoning for this is worth considering, as it helps to articulate the significance of what CID does.

In its most simple form, systemic advocacy identifies and deals with the source of problems. Referring to CID, informants used terms such as 'stewardship' and 'guardians of the system' and they also spoke about the systemic advocacy CID does, about how it brings different parts of the system together. By linking what had happened to individuals on the ground to broad policy directions, they saw that CID's systemic advocacy identified 'pitfalls, opportunities and risks', took 'a longer-term horizon' or pinpointed the need for 'infrastructure'. As one informant involved in policy development explained, this type of advocacy "understands people's stories and tries through constructive dialogue to bring those stories into policy" [National policy leader].

Systemic advocacy can be both proactive and reactive. Setting and driving the agenda was a common descriptor of CID, particularly on issues of access for people with intellectual disabilities and the quality of NDIS, health and criminal justice systems. As one informant said of CID:

the first time in the Australian context the issue of criminal justice contact for people with intellectual disability was really put on the agenda...really drove the agenda in not service sector but in the policy sector for a very long time, and probably still is to some degree... they are always one step ahead of where government policy is ...They did the very same around the NDIS and its introduction...with the policy paper that they released [*The NDIS and people with intellectual disability who live on society's fringe*]. Again, that was at the very forefront of trying to get the agenda of the interface between different systems in terms of the NDIS, and they've been extremely proactive around the NDIS [Professor 1]

On the flip side, CID was seen as the 'go-to people' when policy makers and bureaucrats needed information, advice or help to understand "what's happening on the ground", as one informant put it [National policy leader]. This was conceived as a crucial mediating role, which saved governments and others from having to canvass more widely and synthesise high volumes of information.

So, without that, you're really, somehow, trying to talk to far too many people than you ever can to find out what the issues are. Or they're coming and talking to you, and you don't know whether their view is the same or as consistent with others unless you do that work yourself, whereas if you can go to CID ...So I think it's very important for the system to have the information mediated for them via an organisation like CID [Senior NSW statutory officer]

There are many issues that we might be struggling with or we might want to get a clear understanding about, where we would be thinking, okay, let's approach CID. Either, specific people with whom we might have a chat, or ask CID to arrange for us a group that we can consult with to assist us in terms of getting a better understanding of the issues. [Senior NSW statutory officer 1]

[CID] give me considered, respectful, honest and authentic input ... I think we formed reasonably respectful and professional working relationships. They were kind of like go-to people. If I rang up and say what about this? Are we on track with this? I'd get respectful, frank, particularly useful and practical advice [Senior federal bureaucrat]

Several other informants noted another important aspect of CID's systemic advocacy, suggesting that because CID maintained a broader, longer-term perspective, it acted as the conscience for some services providers enamored with short term fixes. A leader of a service provider said that CID:

...calls you to account... as an executive in a large service provider, I need to make a lot of compromises on a day-to-day basis, and I'd love to have this conscience in the back of my head going - and sometimes it needs to be overt, it needs to be someone like someone from CID or someone else who's going, 'Hang on a minute. Why have you done that?' [Senior service provider]

Many informants felt that there was 'a more powerful need than ever' for this type of advocacy, given the depth of reform and disaggregation of the service system that was

occurring with the implementation of the NDIS. Undoubtedly, CID's systemic advocacy plays key roles for government and service providers and in doing so, its real value is to the lives of people with intellectual disability and their families, in taking up their issues and achieving lasting changes to policy and service systems:

if you're in the system as a family or a person with a disability, having one organisation who's going to pick it up for you is much more important and better than fighting every fight by yourself [Senior NSW statutory officer 2]

Having considered the significance of CID's systemic advocacy to government, and before exploring its impact, it is important to consider the case for CID's dedicated focus on people with intellectual disability and its approach to advocacy.

### **Why intellectual disability specific advocacy? 'this group is not like any other'- 'a group that misses out'**

Unanimously, informants recognised the importance of systemic advocacy focused on issues most relevant to people with intellectual disabilities. Their rationales were diverse, but centred around the recognition of the very specific needs and issues of this group – and in the informants' experiences – the very limited visibility of these issues on policy or advocacy agendas.

...this group is not like any other group in being able to make choices, understand what the potential is for systemic change that would assist them. And nor are they as individuals really, without real systemic advocacy support, able to see the ramifications of things that are coming down the track [Professor 4]

...some of the really complex issues that sometimes do get glossed over in this rush to have everybody under the disability banner. So, we understand that disability as a social experience is one of discrimination...But in terms of particularly things like access and inclusion the issues for people with intellectual disability are very different...They need communication support and cognitive support. They don't need ramps, they don't need lifts... those ways of thinking about what access and support are about have been skewed, in my view, towards disability as a bigger category. And whilst we've made pretty good gains now in physical access and sensory access ...we've made a lot less gains in cognitive access and cognitive support and what that looks like for people. [Professor 1]

Several informants recounted their experiences of involvement in the early work on the NDIS as an example of this group being left out at the policy design stage. Another alluded to health policies being written that were 'weeding out' people who had difficulty with decision making. For example:

the people who were around the table at the scheme design part of the NDIA, I would have to say probably over-represented and disproportionately represented were people in wheelchairs with physical disabilities who were resourceful, well

resourced, articulate, brought to the table a whole set of life experiences, the capabilities and capacities that in fact people with intellectual disability don't bring....But they [people with intellectual disabilities] weren't represented in proportionate numbers and with things that were part of original scheme design and quality and practice definitely didn't resonate and weren't sufficiently nuanced. [Senior federal bureaucrat]

NDIS is at this point in its development, it does not really understand the unique issues associated with people who have an intellectual disability. And I think if there is not a voice to assist those people or their families to articulate what it is that they want and need to be supported appropriately, then that group is going to become a sub-group that is ignored in the new NDIS environment [Senior NSW bureaucrat 2]

We now still see retrofitting of the NDIS around the sorts of ways that people are connecting with the constituents. Sixty percent of people on the NDIS or 60 to 70 will be people with intellectual disability but the scheme itself is designed with a very different idea of who a disabled person is in mind. [Professor 1]

The limited visibility of people with intellectual disability was seen as a multi-level system failure to recognise and adjust processes, or to provide the skilled and continuing support that people with intellectual disabilities need both in speaking out and being heard. As one staff member said:

...it's an ongoing process of support, even our best leaders with intellectual disability, quite naturally, they still need support to deal with the next issue or the next big event that they're to take part in. So, it's not something that's just – you train people up then walk away. [Staff member 1]

...as soon as you get in a room with people who don't have an intellectual disability no one even asks you what you think. That voice kind of gets drowned out. [Professor 1]

A further justification for intellectual disability specific advocacy was sheer numbers. It is no secret that people with intellectual disabilities will make up the biggest group of NDIS participants, with current estimates sitting between 60-70% of all NDIS participants. As one informant pointed out:

So, it's not like they're a small part of the puzzle, they're a significant part of the NDIS program, and if they can't have an advocacy program, probably no-one can justify it. And I think that's even stronger, given that some of the sub-disabilities are things like Down Syndrome and autism, psychosocial disability, which often you have comorbidities with intellectual disability. So, there's even a stronger reach. [Senior NSW statutory officer 2]

Although strongly supporting a specific focus on people with intellectual disabilities, informants acknowledged this was not without its difficulties or a universally held view by disability advocates. One informant noted the conundrum confronting CID of advocating for inclusion through an impairment-specific organisation. In some situations, informants saw a fine line between issues common to all people with disabilities and those distinctive to

people with intellectual disabilities, and also noted that astute judgment was required to decide when differentiation is beneficial or counterproductive. However, most informants highlighted the skills of CID in managing these tensions through their ongoing and productive collaborations with other advocacy organisations.

CID work in a really constructive and collaborative way with the other advocacy organisations, without losing their own – the areas that are a priority for them, they are not grandstanding that over and saying, “Ours are more important than the issues that you -” I think the approach that they have with the other advocacy agencies speaks to the organisation more broadly, which is that the bottom line they just want better outcomes for people with disability and they want to make sure that people with intellectual disability aren’t lost. [Senior NSW statutory officer 1]

...we need to be able to say it's distinct but on the other hand we also need to be emphasising the commonality...it's very clever the way that Australian advocacy organisations have worked that out in terms of knowing when to do things together, when to delegate leadership to one of them and when to be doing things separately so that they are complementing each other's roles but also demonstrating a solidarity. And it needs to be constantly articulated because otherwise there's an argument always from government in terms of oh well you can mainstream this. Not only mainstreaming out disability but within disability mainstreaming out intellectual disability. [Professor 2]

### **Ways of working: ‘not just putting problems out there but providing an alternative way forward’**

Two outstanding features of CID, in addition to its inclusivity, are its solution-focused approach and its commitment to working collaboratively. These features make CID not only an easy organisation with which to work, but one that is well informed and brings together key allies and stakeholders around particular issues.

CID was regularly commended by informants for its deep approach to advocacy, which went beyond banner-waving about things that were wrong. Rather, CID was seen to work by identifying broad problems, breaking the problems down into separate elements, showing how people’s rights were being infringed upon or ignored, providing concrete examples of what this meant to individuals and presenting alternative ways forward. One informant sought to explain CID’s approach as follows:

... presents the issues in a constructive sense that usually is associated with some sort of outcome. So, an example might be what’s happening with people who are on the fringe of the justice system, and CID will provide examples of what those people need, what sort of funding they need, what that funding will help them to do in that sort of constructive way.... [National policy leader]



This solution-focused approach was appreciated by policy makers and service providers, particularly because it often left them with options to use within their organisation that would help them implement meaningful change. For example, they said of CID:

...much easier to work collaboratively with someone who's saying, "We know this is a problem for you, let's fix it", rather than someone that wants to come in and kick you to death because there's a problem. They have been incredibly constructive, they provided lots of good input into policies and procedures. [Senior NSW bureaucrat 2]  
[CID has] a really effective style...being able to actually influence the large service providers [Senior service provider]

...overall, their focus isn't just about, "Here are all the issues and here are all the problems," but it's also about what are some constructive ways that they can get traction on issues, but also present some options moving things forward...then we are able to use that as leverage...to say to the government...these are the concrete things that will lead to very concrete outcomes [Senior NSW statutory officer 1]

The strategic and prioritised focus of CID on searching for solutions to a small number of problems, means that the organisation often works on issues over sustained periods. This is most apparent in the current work of CID within the criminal justice and health systems, which stretches back over almost two decades. On these and other campaigns, CID has worked collaboratively with others to deepen its knowledge base and gain relevant expertise. As one staff member said:

So being well-informed in our advocacy, and that goes back to both getting a voice of people with intellectual disability and their families, and working with the professionals, that's been one of the key ingredients... [Staff member 1]

These connections, particularly with academics and the use of research to inform solutions, was remarked upon by many informants.

CID has been active forever in hunting out people who are doing work which is relevant to them, academics who are doing work that's relevant to them, and of connecting them in and continuing to be in contact. Just ringing when there's something on the go, and saying...could you be involved in this, or what are your suggestions about that. That's a fairly unusual thing, in my experience. [Professor 4]

CID utilises these collaborative networks not only to inform its own advocacy, but also to bring together experts and people across government, at various levels, political or bureaucratic, who can be influential in reaching policy solutions. Examples of this are the CID roundtables on mental health, health, complex needs and the National Disability Strategy and conferences on the NDIS, inclusion and making change. As part of wider campaigns, these events have successfully opened new agendas or nudged policy changes by bringing into the arena the disparate groups that need to work together to make change.

Talking about the role this approach to advocacy plays, policy makers and service providers said:

CID organised a very big – it was in Canberra, and it was a roundtable between the mental health sector, intellectual disability sector, and the community health sector, and that sort of bringing together of different parts of the community helping system was very effective. [Senior NSW statutory officer 2]

And so, they are making an impact politically, they are around the right tables, they are really influential with- anybody who needs to be in the tent, basically, is pulled into the tent. [Senior service provider]

...the Newcastle conference that they ran about two or three years ago... they were gathering together a consensus and a view and an understanding around the NDIS implementation. So, this kind of capacity building, information-generating questions but including the people with intellectual disabilities, you know I see that their role was kind of quintessential. And you know, also they had non-intellectually disabled experts there as well. [Professor 3]

...we had Bruce Bonyhady, chair of the NDIA, we had senior people from there, from academia, from a really broad range of key people from around Australia... [A bureaucrat] in Social Services said he'd never been to something that was just so – of this kind, it just brought together so many of the key really valuable things in one room. That led to a pretty broad consensus on the key elements of what should be in the Quality and Safeguards Framework. We never – at those round tables, we haven't sought a clear consensus statement, because that's really hard with so many government agencies involved. But what we've more done, and this has worked well, it's CID's report on the round table, but very much informed by all the stakeholders. [Staff member 1]

### **Impact of CID: 'key tangible things have resulted from their actions'**

We have already alluded to the significant contribution CID makes to the processes of government, by capturing and injecting the voices of people with intellectual disability into policy in order to counter the exclusion of their issues from such debates. CID has also brought lasting structural changes for people with intellectual disability, particularly in respect to mainstream services. The health and criminal justice campaigns, unique exemplars of the organisation's collaborative and solution-focused advocacy, are also illustrative of CID's tangible impacts upon society. Other tangible achievements range from leading advocacy associated with the responsiveness of the NDIS to people with intellectual disability, changing community expectations about the participation of people with intellectual disabilities in civil society and building longer term capacity for this. In these next sections, we summarise some of these achievements, all of which stem from CID's role as central to driving a 'social change agenda in intellectual disability in New South Wales...[and] more nationally for quite some time'.

**Criminal Justice System: ‘opened up to a number of people including politicians, a world that they have absolutely no idea about’**

CID first took up the over-representation of people with intellectual disabilities in the legal system in the mid-1980s, in partnership with the Intellectual Disability Rights Service (IDRS). The organisation made little headway until the 1996 NSW Law Reform Commission Report on *People with Intellectual Disabilities and the Criminal Justice System*, which recommended legal and service system development. But as with many such reports, little action followed and CID recognised that “you can have the best legal system in the world, but if people aren’t getting the human service supports they need, they may just be back in trouble again tomorrow” [Staff member 1]. After considerable lobbying, CID and IDRS were commissioned to develop a comprehensive framework of the human service system needed. The Framework Report was published in 2001. It was remarkable not only for breaking new ground about services needed by this group, but also for the processes of its writing which involved consultations with government agencies and clinical specialists. By the time the report was published CID and IDRS had crafted a broad consensus about what was needed and the inclusion of a key senior disability bureaucrat on the reference group helped to ensure an internal champion for its implementation. This report led to an immediate policy change and in time, a major new service for up to 400 people as they came out of the criminal justice system. This successful implementation of this policy was summarised by a staff member as follows.

So shortly after we released the report, ADHC [Aging Disability and Home Care] changed its policies to make people in trouble with the justice system a priority group for service provision. And that was by contrast with the earlier policy that basically these guys are only mildly intellectually disabled, so they’re not our priority. Secondly, what became known as the Community Justice Program (CJP) was funded... it’s led to over 300 people with very serious histories of offending, who you couldn’t really expect the mainstream disability system to [support] they didn’t have the specialist skills to work with, it’s led to a range of tailored accommodation support packages for all those guys, and that’s everything from highly supervised and structured group homes for some people, such as people with long history of sexual offending, through to drop-in support in your own public housing, so that’s again something that I would confidently say would have been very unlikely to have happened without our advocacy, definitely. [Staff member 1]

As one academic said, the CJP has become the ‘envy of other states’ and she and others supported the claim that these changes would not have happened without CID.

Well, there's absolutely no question that the work that Jim and others did – late '90s, their Framework report, was really an effective means by which to bring to the surface systemic issues, as well as the individual issues going on for people with intellectual disability who are involved in the criminal justice system...we would not have the CJP, which has been going now for a decade. And that would mean that currently 400 people with intellectual disability coming out of prison would not have a support service, and they would be back inside – my research shows they'd be back inside in a flash. [Professor 4]

The benefits of these changes are difficult to quantify, but are likely to have included reduced recidivism among people with intellectual disabilities, reduced costs in the justice system, fairer legal processes and better lives for people with intellectual disabilities.

**Health Services: 'the establishment of those health clinics and that leadership body around health- that is a major social change'**

CID advocacy about access to quality health services for people with intellectual disabilities started around 2000. From the outset, it had dual goals: improving the responsiveness of the mainstream health system, and establishing specialists in intellectual disability health to back up mainstream services. Led by CID, but with strong alliance to leading researchers in the field who demonstrate continuing health inequalities, this advocacy has had a major and lasting impact at both national and state levels in respect to health and mental health services.

I just think that there are some key issues relating to some of the mainstream services in New South Wales like Health, and Health in particular, where CID leads that – it has led that work over an extended period of time. [Senior NSW statutory officer 1]

Another major national change achieved in 2006 was specific Medicare items for annual comprehensive health assessments of people with intellectual disabilities. This campaign was led by CID in collaboration with academics and medical associations. At its heart was Prof Lennox's ground-breaking research about 'additional time that it takes to do a really good assessment of people with intellectual disabilities, many of whom can't speak and enunciate their symptoms' and the value and viability of conducting annual health checks.

Other changes have been incremental, such as the development and introduction of training programs for GPs and hospital staff, which had difficulties with take-up amid crowded continuing medical education. However, persistence for more structural initiatives paid off. And a breakthrough occurred after CID's 2006 NSW roundtable on health, at which senior health bureaucrats and representatives from the medical profession heard directly from people with intellectual disabilities, family members and health professionals about the pertinent issues. Commitment was made for a New South Wales Health framework to

improve the health of people with intellectual disabilities, and over time, the establishment of an intellectual disability advisory committee of NSW Health. Conceived as a joint project between NSW Health, ADHC and CID, the most significant initiative flowing from the framework has been the establishment of three pilot intellectual disability health teams, to trial approaches to specialist backup for mainstream services. The pilot teams have been evaluated and CID has been advocating for a statewide rollout of these teams.

An offshoot of this work has been the establishment of an Intellectual Disability Network in the NSW Agency for Clinical Innovation.

CID work is beginning to leverage change to mental health services where attention to people with intellectual disability in service planning has been largely missing. For example, there was a general commitment at the last federal election from all parties to include a focus on people with intellectual disabilities in Primary Health Networks and the NSW Government supported the call for this to be a priority group in the 5<sup>th</sup> National Mental Health Plan. As a staff member said,

We also led a really big national round table about mental health and intellectual disability. That was in close liaison with Professor Julian Trollor. We had 150 key people in Canberra for that one, and that did lead to basically a consensus communique. The world hasn't been reinvented, but there's been a lot of useful incremental change that's flowing from that, there's going to be another similar round table next year which Julian's leading this time, but with us as a central partner [Staff member 1]

**NDIS: at the very forefront of trying to get the agenda of the interface between different systems in terms of the NDIS**

As many informants pointed out, CID has taken 'incredible leadership around the NDIS' as the many facets of this system reform are developed. Most evident is their role in the advocacy leading to an Intellectual Disability Reference Group. This group was established soon after the 2015 CID Newcastle conference, which brought together multiple perspectives on the many ways that people with intellectual disability had been left out the design of the NDIS. CID has undertaken its own policy and consultative work to formulate major submissions on issues such as the Quality and Safeguarding Framework, the Information, Linkage and Community (ILC) component, and responsiveness to needs of people with complex behaviour in contact with the criminal justice system. The impact of these are clearly visible in some NDIS positions and their value marked by the ongoing advice and consultation with CID by NDIA. CID has also been at the forefront of identifying the

potentially high costs of failing to consider and resolve the demarcation of responsibilities of the NDIS and state government agencies, such as health and justice, and the dangers of the NSW Government losing past gains, particularly around the interface of criminal justice and human services. One national policy leader suggested that CID's advocacy around the NDIS was playing a cost saving and risk management role for government.

...it's in our interests as an insurance scheme that people who are on the fringe of a funding package – because not everyone who CID represents would be eligible for an individual package under NDIS. It's in our interest that those people continue to be supported in the community with information and linkages, rather than cost us, ten, twenty, thirty thousand dollars. So, there's an almost risk management role that CID play...I'm not saying they're the only one that does this, but there's a risk management role that organisations like CID play in protecting the overall funding model of the NDIS. So, it's a big role for the big success of the system. [National policy leader]

### **Changing community expectations: 'provides an example to the rest of us about best practice should be done'**

CID acts as role model, exemplifying to other organisations that participation by people with intellectual disability is both possible and how it can be done. As already discussed, inclusion is embedded throughout the organisation, its internal governance and advocacy work. This in itself is rare among organisations that put issues for people intellectual disability at the forefront of their work. As such, it plays an important educative function for similar organisations. It is also important for government and other organisations where expectations of participation by people with intellectual disability are growing often in the absence of guidance about how this might be achieved. Informants pointed both to the role of CID in changing expectations and the influence of their exemplary practice,

...you wake up and say, "this is not the way it was a few years ago." So, I'm seeing that. I'm very excited about that, and I would see CID as having been, like – you know, a very important part of getting to that. They might not see that as a campaign in itself, but everything they do demonstrates that, and they live that, and demonstrate that so other people can watch them. [Senior NSW statutory officer 2]

the bigger issue is cognitive access and the practice element is support for cognitive access really. So, I think one of the things they've done is - I mean by their own practice you can see they just are exemplary in that space. [Professor 1]

And because the way that they do things challenges the way that most organisations, if not all organisations, work then they're an extremely good example of why things need to change and how they can change. And that's because from their governance structures through to their daily work it is a demonstration of that then means that for someone like me it's easier to challenge when people say oh yeah that's all very well

but it can't be done. Because I think what's unusual about CID is that they demonstrate it can be done and they're that's doing that. [Professor 2]

Some informants talked more generally about the impact of CID's inclusive approach on changing family and community attitudes towards people with intellectual disabilities and their place in society.

I think just the way they operate has made a huge difference, to the way people see people with disabilities, who they are, in positions of power and authority and not just living their lives but actually influencing others. I think that's probably the most significant thing that they've done. [Senior service provider]

...think fairly successful in getting people to understand that there are people in our community who do not function perhaps as well as we might expect people to function but they have still got rights and they still can work effectively in our community. I think CID has been very, very effective in that and I think in encouraging individuals to try and realise their potential and families to support them to do that. [Senior NSW statutory officer 2]

This was also the view held by one of the leaders of CID, who said:

I think that CID has done very good work with society, telling them about how people should be able to speak for themselves and to advocate in a better way. [CID board member]

**Building leadership and capacity of people with intellectual disabilities: 'I'm not sure that those individuals would have an alternative opportunity to develop those skills if it wasn't for CID'**

By the very way that it works, as well as their specific leadership programs, CID creates a legacy of increased potential for inclusion by swelling the numbers of people with intellectual disabilities with experience and confidence as advisers and educators to government, service providers and academics. Attention was drawn for example, to the current membership of the Disability Council, the NSW Government's disability advisory committee. The Council's three members with intellectual disabilities had all been part of CID training initiatives and two had served as CID committee members in the past. Others suggested that without CID, there would be no place that people could go to gain the skills or confidence to sit on advisory or reference committees, or participate in education such as that provided to members of the Guardianship Division.

They currently have produced dozens of people with intellectual disability who are distributed around New South Wales as leaders and who have the confidence to speak, confidence to say what they think – you know that great saying 'truth to power'. And have the confidence to do that to government, to local government, to NGOs, if CID was not there, they would not be there doing that... The New South

Wales Disability Council would not have anyone with intellectual disability on it, were it not for CID. [Professor 4]

Important too is the impact that being included has on the lives of people with intellectual disabilities involved in CID.

But just on a day-to-day basis, the impact on people with intellectual disabilities that are involved very much in the running of the organisation are the public face of the organisation, so the impact on them personally I think has been quite amazing, looking at people who really have a really valued role. [Senior service provider]

### **Last Words**

This report summarises the views of 11 senior external peers, who have engaged with CID as part of its systemic advocacy work over the last 25 years, as well of those of staff and a leading member of the organisation. It has tried to capture the enormous standing of CID among senior government and service personnel and its contributions to lasting social change for people with intellectual disabilities. It is an organisation that models inclusion of people with intellectual disability in everything that it does, where people with intellectual disabilities work in alliance with skilled supporters and professional advocates, and whose advocacy is grounded in the experiences of people with intellectual disabilities. The organisation's systemic advocacy plays important roles for government by connecting parts of the system together and translating individual experiences into policy issues. Its work exemplifies the possibilities of inclusion and builds capacity for this to occur. CID has driven a NSW state and, to some extent, a national agenda to ensure issues specific to people with intellectual disability are not ignored as they so often have been the past. We have identified some very specific structural changes, particularly in health and criminal justice, but also in respect of the NDIS as a direct result of CID's work. We have pointed to its collaborative and informed approach to advocacy, and its credibility as a more informal advisor, consultant and educator to government and services.

A final question we asked all informants was to consider the possibility of the CID ceasing to exist. Their comments included words and phrases such as 'horrendous', 'shocking', 'a much poorer community' and 'can't identify who would be filling that gap'. Informants explained how CID occupies a very significant space, and how its loss would leave a void that would take years to fill. Indeed, many thought that the organisation would be reinvented within five years in some form or other, simply because the health and human service systems would be unable to function without the connections CID provides between its various parts that



impact on the lives of people with intellectual disabilities. Many informants intimated that the absence of a body taking the type of holistic view that CID takes would be widely felt:

We see their work almost week in week out in terms of particular initiatives. Promoting the rights of people with disability, and with a particular emphasis in terms of capacity building and ensuring that those they represent, their voice and their personal circumstances are made stronger over time, and then the community has benefited enormously from their work. We would be a much poorer community were it not for the voice of CID and its representatives [Senior NSW statutory officer 1]

I think that it would make people with intellectual disabilities much more vulnerable to exploitation, ... you'd be closing a really important voice. And I've got no doubt that somebody will be coming back and saying, "We need this into the future and it should happen." Because it is just so obvious... So I think it'd be a void. I think it would be shocking. There's many organisations that I like, but there's few that I'd be nationally concerned if they closed down, but this is one of them. [Professor 3]

Governments would lose an organisation that held them to account, a critical and effective means of involving people with intellectual disabilities in service design and a key way of understanding whether policy intentions and service design reflected needs on the ground.

Government needs to recognise that if they have an organisation which is holding them to account and they mightn't like them very much for doing that, they're also an organisation which is saying 'but, we've got some solutions, and here are some solutions that will make you look good, if you pick them up.' [Professor 4]

If you're designing something and you don't have that direct contact with the end users, be they people with intellectual disabilities or carers or supporters or friends or the community that they value it won't be as good as it could be. That's the voice that CID brings. [Senior federal bureaucrat]

There was a sense of doubt that the disabled persons' organisations funded by the national peak groups program could replicate the systemic, inclusive and intellectual disability specific advocacy that is so effectively undertaken by CID. Leaving resource capacity aside, these organisations have a national mandate, are identity based and generally have a broad cross disability focus.

And where will the systemic advocacy be once mainstream services take over, providing – well, they already do, but they are then tasked by the NDIS officially to provide the kinds of health supports, mental health supports, which previously an organisation like CID would be in there advocating with health, and with housing, and so on, to ensure that these things happen not just for one person, but for everybody. [Professor 4]

So, we need the education system, the health system, the housing system, the justice system, and the NDIS that has built this system to all work together, and we need organisations that are divorced from all of those and looking at the big-picture outcomes. We need them... [National policy leader]

