FROM RIGHTS TO RESULTS - SYSTEMIC ADVOCACY AND LEADERSHIP BY PEOPLE WITH INTELLECTUAL DISABILITY

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Where CID has come from

NSW Council for Intellectual Disability (CID) is a disability rights organisation led by people with intellectual disability. Its core role has always been as a systemic advocate. In recent years, it also has carried out wide ranging projects under the Information, Linkages and Capacity Building arm of the NDIS.

CID was formed in 1956 as a peak organisation for non-government service providers. In the period after World War 2, parents had established non-government services in their quest for a better life for their sons and daughters than was available in the government run institutions.

In the late 1970s, a parent advocacy movement became prominent separate from the service providers and parent advocates became leaders in CID. The first parent advocate to be chair of CID was Jeanette Moss in 1982. One of the first things that Jeanette did as chair was sit down with three emerging self advocates, David Gant, Robert Strike and Trevor Whiddon, to discuss what role they would like in the organisation. Before long, David and then Robert became members of the board. In 1990, David became the first person with intellectual disability to be chair of CID. Since 2002, all chairs of CID have been people with intellectual disability and since 2004, the constitution has required that a majority of board members have intellectual disability.

CID gradually developed strong support structures to enable board members with intellectual disability to effectively carry out their roles including Easy Read board papers and a board participation worker supporting board members to prepare for meetings and carry out other leadership roles.

The other members of the board continue to be family members, other advocates and disability professionals.

This majority rule by people with intellectual disability melded with the inputs from other board members provides a rich basis for setting key directions in the organisation.

CID’s systemic advocacy has developed over the years from lobbying on behalf of people with intellectual disability to multi-strategy advocacy with people with intellectual disability taking central roles.

What systemic advocacy means at CID

Cocks and Duffy (1993) set out five governing principles to characterise and provide direction for advocacy:

1. Advocacy is on the side of disadvantaged people.
2. Advocacy is concerned with genuine life needs.
3. Advocacy strives to minimise conflicts of interest.
4. Advocacy engages in vigorous action.
5. Advocacy has fidelity to disadvantaged people.

The Disability Advocacy Network Australia (DANA 2020) describes advocacy as promoting, protecting and supporting a person’s, or group’s, full and equal human rights. Advocates support or work on behalf of a person with disability to help them to speak out and defend their rights and interests. Systemic advocacy works to solve an issue that affects a large group of people with disability.

Taking account of these descriptions, CID defines its systemic advocacy as acting with vigour and minimum conflict of interests with people with intellectual disability to change the community so that it protects the rights of people with intellectual disability, includes everyone and supports people well.

CID’s advocacy activities include running campaigns, taking up issues with key decision makers, making submissions to inquiries, running roundtables and similar events, and social and mainstream media that highlights problems and solutions. Central to these activities is identifying a problem, considering what action will fix the problem and pressing for that action to happen.

Over the decades, CID has developed an advocacy style which is: informed by the experience of people with intellectual disability and their families, research evidence and professional best practice; highly principled in our goals but pragmatic in relation to short-term achievables; assertive and persistent but also building strong working relationships with key decision makers; and collaborative with other advocacy groups, academics and professional allies.

CID sees development of positive working relationships with decision-makers such as ministers and senior public servants as very important to ensuring open dialogue, receptiveness to our ideas and inclusion of us in early stages of decision making. At the same time, we are careful not to be compromised in the independence and vigour of our advocacy.

We usually find we can achieve this balance in our dealings with decision makers and this leads to better outcomes for people with intellectual disability. However, sometimes relationships become frayed, in particular when governments make decisions without consultation and that we see as having negative repercussions for people with intellectual disability. Also, decisionmakers do vary in their respect for advocacy and its independence. Many decision makers respect vigorous advocacy as inherently valuable. Some see it as unreasonable criticism.

CID's dedicated advocacy staff (a senior advocate, a campaigning specialist and an advocacy and policy officer) work with people with intellectual disability in a number of ways: consulting about problems and solutions with board members, an advocacy group, staff and other individuals with particular experience; developing the capacity of people to be leaders in our systemic advocacy; a person with intellectual disability taking a lead role in major meetings with politicians and other key decision makers; supporting our advocacy group of people with intellectual disability to advocate on issues important to them; and supporting people to actively participate in advocacy related events, including as keynote speakers and event chairs.

Shu Hua Chan's advocacy journey

Shu moved to Australia from Hong Kong with her parents when she was 13 years old. Her grandma was already living in Australia and was ill with cancer. Shu had been cared for by her grandma when she was little so was very close to her.

Shu attended a special school instead of going to a mainstream school but says that the teachers were not very interested and she didn't feel like she learnt very much.

After she left school, she attended TAFE where she learnt to read and write better, she also did maths and ceramics.

Shu's mum took Shu to Brain Injury Australia and an advocate there suggested she might enjoy volunteering at The Multicultural Disability Advocacy Association (MDAA). Shu took her up on this. After a few years of volunteering, Shu became an employee at MDAA and has worked there for more than 17 years. Early on at her time at MDAA, Shu moved out from the family home and lived independently in public housing.

The same advocate who had suggested that Shu volunteer at MDAA later suggested that she go along to CID and join their advisory group Speak Out Reach Out (SORO).

In the beginning, going to SORO was partially a social event for Shu but she really started to enjoy the skills she was learning like speaking up for what she wanted. At the time, SORO acted as an advisory group for CID's board, letting the board know what they thought were the most important issues in their lives, running information forums and putting submissions to the government. SORO also acted as a training ground for CID's board, giving SORO members a chance to learn vital professional skills, such as how to chair a meeting. After a few years with SORO, Shu decided to run for the board and was successful in gaining a place. Initially, she was an ordinary board member, then vice chair for a couple of years and eventually chair for the last three years.

In the meantime, Shu's mother has passed away and Shu is now her father's carer, so she has become familiar with the health sector from a variety of angles. She knows a lot about how people with intellectual disability are talked down to or not listened to in the health system and about how many people with intellectual disability do not get the treatments they need.

Shu especially enjoys working in the health space, doing systemic advocacy both for people with intellectual disability and for those from a CALD background. She also speaks Mandarin and Cantonese.

When CID was planning the Our Health Counts campaign in early 2019, Shu was keen to be involved. She launched the campaign with a video speech, led a CID delegation to Deputy Labor Leader Tanya Plibersek and gave the opening address at the national Roundtable on the Health of People with Intellectual Disability.

Shu has spoken at major conferences including the keynote address at the 2019 ASID conference on which this article is based.

Shu has become a leader and an advocate but says it is not easy. She says that you need to have support from other people, such as staff at CID or her boss Susan at MDAA, to be able to keep speaking up, to be able to say what she needs, to be able to give her opinions in a strong voice and to see herself as a leader.

A focus on interests

CID's approach to advocacy is influenced by the theory of principled negotiation (Fisher and Ury 1981, Ury 1991, Fisher, Kopelman and Schneider 1994). Instead of just focusing on a position, for example no person with intellectual disability should go to gaol, we would think about the interests of people with intellectual disability, for example being treated fairly by the police and courts and having the support services they need to lead positive lifestyles. We would then think about options for achieving our interests including better training for justice personnel, changing sentencing laws, creating court diversion schemes and ways to improve access to disability support. We would think about these options with a focus on the ones that will best advance our interests and appeal to the interests of relevant decision-makers who may here be senior bureaucrats, ministers and the judiciary. A good outcome or set of outcomes from this process would be one that is the best available alternative, satisfies the interests of key players especially those of people with intellectual disability, has legitimacy (that is can be measured objectively, for example through being based on the research evidence), includes compliance prone commitments (that is, clear incentives for the decision maker to act on their commitments) and that builds our relationships with decision-makers.

The interests of decision makers can vary widely with some common interests being career advancement, getting votes at the next election, recognition for positive reform, saving government money and usually but not necessarily a desire to improve the lives of people with disability. As well as taking the particular decision maker's interests into account in advocating an outcome, it is important to show how those interests will be served if the decision maker commits to the outcome, for example providing evidence of potential budget savings or that you have a broad constituency of voters who are hanging on whether the decision maker acts.

A limitation of interest based negotiation is that it may lack a clear goal to mount a campaign around and can lead to long discussions with no clear outcome. However, interest based thinking is still a valuable informant of what goal to set in for a campaign and in the negotiations that may occur once a decision maker has accepted that they need to take some action.

We will now further explain our approach to systemic advocacy using the case study of CID's advocacy for action on health care in the lead up to and after the 2019 federal election.

Our Health Counts campaign – crafting the ask

An initial question is whether this is the right time to pursue a particular issue or campaign. Is the time ripe (or is the issue so important that we need to pursue it even in an unreceptive environment)?

As we approached the 2019 federal election, CID saw scope to mount a campaign for strong pledges of action on health care by the political parties. In the previous two years, the research evidence on health inequalities for people with intellectual disability had strengthened considerably, in particular with findings of Trollor, Srasuebkul, Xu and Howlett (2017) that people with intellectual disability in NSW were suffering 38% potentially avoidable deaths as compared with 17% for the general population and dying 27 years earlier. There were particular problems in primary care with underdiagnosis of chronic health conditions and lack of adequate management of risk factors. (Weise, Trollor, Pollack and Britt 2016; Weise, Pollack, Britt and Trollor 2016; De Winter, Bastiaanse, Hilgenkamp, Evenhuis and Echteld 2012)

The research also showed that, in the average medical degree, students were only receiving 2.6 hours training in the health needs of people with intellectual disability and the majority of nursing schools had no specific content on these issues (Trollor, Ruffell, Tracy, Torr, Durvasula, Iacono, Eagleson and Lennox 2016; Trollor, Eagleson, Turner, Salomon, Cashin, Iacono, Goddard and Lennox 2016).

As well as the human cost of inadequate health care, the research suggested great financial cost to government in not meeting the needs of people with intellectual disability. People with intellectual disability had twice as many hospital admissions as other people and each admission cost twice as much. (Trollor, Reeve and Srasuebkul 2016)

The NSW government had taken substantial action on health inequalities, in particular by establishing a statewide network of intellectual disability health services to provide specialised backup to the mainstream health system. From our Deadly Disability Discrimination campaign, which had influenced action in NSW, we had a strong network and support base for moving to a national campaign. Finally, it was clear that the federal election campaign was going to be hard fought.

The key informants of our campaign were the experiences of people with intellectual disability and their families, the research base and consultations with allies in the intellectual disability health and advocacy spheres.

In deciding what were our asks in the campaign, we focused on what would resonate with both key decision makers and our support base. We consulted widely, including with mainstream health bodies. We considered potential cost savings to the health and disability service system from improved health care.

We finalised our three asks in consultation with our national organisation and campaign partner Inclusion Australia, and campaign collaborators the Australian Association for Developmental Disability Medicine, Down Syndrome Australia and the Department of Developmental Disability Neuropsychiatry University of New South Wales.

We resolved on three asks in our campaign: an intellectual disability program in each of the 31 primary health networks (PHNs) around Australia; a curriculum enhancement in university medical and nursing schools; and an inquiry into other reforms needed in the health system.

The federal government funds PHNs to work with general practitioners and other primary health services with key objectives of increasing the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and improving coordination of care to ensure patients receive the right care in the right place at the right time (Department of Health 2020). Consistent with the way in which PHNs work with other priority patient groups, we sought a program in each PHN that would enhance access to and skills of primary health services for people with intellectual disability, including health promotion and prevention and the use of Medicare annual health assessments.

In February 2019, we released a detailed statement of the commitments that we sought from the Australian political parties. This included the research justification for our asks, a $50 million costing of the three asks and details of potential budget savings that would flow from improved preventative and early health care, notably including the cost of treatment of avoidable chronic and acute conditions, the cost of avoidable hospitalisations, savings to the NDIS from reduced support needs and savings to the economy from increased workplace participation by people with intellectual disability and their families. (Council for Intellectual Disability and Inclusion Australia 2019a)

Mounting the campaign

Early in the campaign, we had a very constructive meeting with a Deputy Secretary of the federal Department of Health. She showed a clear and positive understanding of the issues we were raising and of the strategies we were suggesting. It is important to seek to engage senior bureaucratic support before going to the relevant minister. Ministers will look to senior bureaucrats for advice in relation to proposals and rely on them to pursue actions that the Minister may initiate. If key bureaucrats are not onside, progress may be stymied or delayed.

Ideally, as a campaign unfolds, all key players are saying, “Yes Minister. Do it!” The broader the support, the more likely the Minister is to act. If any key players are against you, the chances of the campaign succeeding are much reduced.

We obtained very strong eminent support for our campaign through an open letter with over 100 signatories, including, presidents of medical colleges, health deans and leaders in disability rights and advocacy. (Council for Intellectual Disability and Inclusion Australia 2019b)

Meanwhile, led by our campaigning specialist and CID’s communication team, we formulated messaging and imagery for a campaign around the banner Our Health Counts. We launched the campaign with a powerful video presentation by our chair Shu Hua Chan, who highlighted the avoidable deaths experienced by intellectual disability and concluded, “Our health counts. Can we count on you?”

We launched a petition for the campaign which was ultimately supported by over 7,500 people. (Council for Intellectual Disability 2019a)

We obtained substantial mainstream media support for the campaign, for example around the enormous challenges experienced in the health system by Ryan Kelly, a young boy from Tasmania. The campaign featured a video story about Ryan told by his mother. (Council for Intellectual Disability 2019b)

Personal stories are very important in adding a human interest element to a campaign and in obtaining mainstream media coverage.

We also used social media considerably to advance the campaign, including Facebook and Twitter.

We engaged with advisers to relevant ministers and shadow ministers and with the Australian Greens.

Through our networks and those of our campaign allies, we supported visits by local constituents to numerous members of parliament and candidates, particularly in marginal seats.

As our campaign unfolded, the government established the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability which clearly would be a forum that would highlight inequalities experienced by people with disability in the health system.

The Greens were the first party to take a position on our campaign and fully committed to our costed proposal of $50 million over three years.

Obtaining meetings with senior ministers and shadow ministers in the lead up to election can be challenging but we were assisted by engaging first with their advisers and support from other senior politicians with whom we had existing relationships.

Ultimately, we obtained meetings with Health Minister Greg Hunt and Shadow Minister Catherine King on the same day, seeing Ms King at Sydney airport and Mr Hunt in his office in Melbourne.

That meeting with the minister

Meetings with ministers are usually hard to get and are often a one-off opportunity to progress your current goals and impress the Minister as people whose views are worth listening to. Meetings are usually scheduled to last thirty minutes and often end up being significantly less than that. Planning is key.

Usually, your delegation should be small so as to assist a focused conversation. CID’s delegations usually include one of our leaders with intellectual disability and our CEO or Senior Advocate. We may also include a parent advocate and/or a lead researcher or professional. The delegation should seldom be more than three people.

We prepare a one-page well-spaced outline of the key points we want to leave with the Minister. These usually cover who CID is and represents (to show that we are a strong representative voice), the size of the population affected by the issue (to show that the issue we are raising affects a lot of people and voters), a definition of the problem we are bringing with a reference to research evidence, our proposed solution and any research base for it, the consistency of our proposal with existing party policies and initiatives, the broad support base for the proposal and the potential cost benefit of it (both in human terms and government budget implications).

In the meeting, we ask the Minister to first hear from the person with intellectual disability. The person may read a short speech or have a question-and-answer discussion with one of us advocates, depending on the preferences of the person. The person will often speak of their own experiences or those of people they know. This start of the meeting is an important demonstration of the centrality of people with intellectual disability in the issue and commonly creates a positive atmosphere with the Minister.

If a family member is present, they will usually tell of a personal experience that illustrates the problem we are taking to the Minister.

After that beginning, the way meetings proceed varies a lot with the wishes and style of the Minister. You may be allowed to outline your case and then the Minister responds and asks questions. Alternatively, the Minister may move into a discussion straightaway. You need to be agile and flexible to keep the meeting on topic and make your key points. The Minister may seek to move the conversation to other matters either because she or he is more interested in those or to avoid coming to any conclusion on your topic.

The Minister will usually have been briefed by bureaucrats and/or ministerial advisers. You should try to draw out and respond to any negative arguments from them.

It is vital to keep your message simple and clear. Minimise the detail you provide. Before and after your meeting, the Minister will deal with countless issues that day. If he or she does not come out of your meeting with a clear understanding of the problem and what to do about it, you may have lost your chance to get action.

We aim for the meeting to finish with a clear commitment to action by the Minister. Ideally, this will be full agreement to our proposal. It should at least be commitment to next steps for taking the issue forward, for example linking you to relevant bureaucrats with a view to the issue being further explored and options going back to the Minister.

Our meetings with Minister Hunt and Shadow Minister King went well. Ms King was clear that Labor may be open to making a commitment but that our $50 million ask was not feasible. She asked us to submit a revised ask to pilot our proposed primary health network programs in four PHN’s and to develop and trial a curriculum enhancement in medical and nursing schools. Labor subsequently committed to $9.5 million over three years for these purposes.

Minister Hunt was clear that there was a major problem to be addressed and committed to holding a roundtable to provide advice on action. This was obviously a much less specific promise than that from Labor but we were encouraged by the federal Department of Health immediately, and prior to the election, engaging with us in organising the roundtable. The roundtable occurred in August 2019 and a draft roadmap of action was released (Department of Health 2019). A follow-up roundtable was scheduled for April 2020 but was postponed because of the COVID-19 pandemic. However, in the meantime, the Minister committed $6.5 million to initially rolling out our primary health network programs in four PHNs with a view to national rollout after four years. An expression of interest process followed to decide which PHNs were to be funded.

Advocacy is a long haul

Sometimes, you get quick results from an advocacy campaign. More often, achieving major progress takes a medium to long-term approach. For example, CID’s Hard to Swallow campaign for the National Disability Insurance Agency to accept responsibility for swallowing therapy took less than a year. However, our campaign for a network of intellectual disability health services across NSW took over 15 years, punctuated by an in principal acceptance of the need by NSW Health in 2006, the funding of three pilot teams in 2011-2012 and then the funding of further services in 2018.

The Our Health Counts campaign has achieved commitments to a national network of intellectual disability programs in primary health networks and the rollout of programs in four lead sites. We also have a draft roadmap and a very strong collaborative relationship with the federal Department of Health towards further action. However, undoubtedly, ongoing strong and strategic advocacy will be needed to ensure that the PHN programs are rolled out nationally, that a strong roadmap is finalised and, most importantly, that it is implemented.

Persistence, relentlessness and regularly reflecting and modifying strategies are all important to successful systemic advocacy

While an advocacy campaign should start with a clear plan, the plan also needs to be flexible and continually reviewed in response to whether initial strategies are working and changing circumstances. For example, a recent campaign of CID was aimed at reversing a NSW government decision to stop funding the Cognitive Impairment Diversion Program, a pilot program achieving good results for people with cognitive impairment facing charges in local courts. From the start, one of the things we emphasised was the inclusiveness of the program with 26% of its participants being Indigenous Australians. When events in the United States led to a major focus in Australia on the overrepresentation and deaths of Indigenous people in the justice system, we further emphasised the importance of the CIDP to Aboriginal and Torres Strait Islander people in collaboration with the First Peoples Disability Network.

Sometimes, reflection shows that the time was not right for a campaign and we suspend or reduce emphasis on the campaign until times are more opportune.

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 disability support and mainstream services; more valued and included lives in the community; better protection of people’s rights to be free from abuse, neglect, exploitation; and 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 governments include: the capacity to obtain informed input to policy and service development; assistance and guidance in delivering on governments’ obligations under the Convention on the Rights of Persons with Disabilities and National Disability Strategy; protection of governments’ investment in the NDIS by it being more responsive to the wants and needs of people with intellectual disability; early warning when government and community services are not working; cost savings through earlier and better integrated responses; improved understanding and commitment from civil society to working towards full inclusion.

People with intellectual disability need their own systemic advocate

Since CID was established over sixty years ago, it has been recognised in NSW that people with intellectual disability need their own systemic advocacy voice. This was also the case at a national level until recent years when the federal government moved to funding national systemic advocacy on a cross disability basis including specific groups representing Indigenous Australians, people from culturally and linguistically diverse backgrounds, women and children and young people. We support the need for these groups. However, we do not think this should be at the expense of groups representing people with particular disabilities.

Specifically, we are clear that people with intellectual disability need their own representative systemic advocacy group. People with intellectual disability have particular needs which are often different to people with other disabilities, for example consideration of cognitive access to mainstream services as compared with the much more high profile physical and sensory access. As Bigby (2020) identified, there were major flaws in the design and implementation of the National Disability Insurance Scheme for want of recognition of and response to the needs of people with intellectual disability. A scheme intended to be focused on choice and control by people with disability did not at all adequately accommodate the needs of people with intellectual disability for access, planning and plan implementation processes focused on their cognitive needs including for advocacy and support in decision making.
Consistent with the Convention on the Rights of Persons with Disabilities Article 29 (Participation in public life), 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 challenging to provide these leadership opportunities in a cross disability organisation which quite rightly is seeking to accommodate and represent the voice of people with a wide variety of disabilities and needs. CID ensures leadership by people with intellectual disability through 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.

A recent review of advocacy funding in NSW has affirmed the need for people with intellectual disability to have their own systemic advocate. The review recommends continued and expanded funding of individual and systemic advocacy in NSW, with seven groups funded for systemic advocacy, comprising a cross disability group and groups representing people with intellectual disability, people with physical disability, people with psychosocial stability, people from culturally and linguistically diverse communities, people from Indigenous communities and a group for families and carers. (NSW Ageing and Disability Commissioner 2019)

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