

A DISCUSSION PAPER

# Strengthening the Disability Voice in Tasmania

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## Acronyms used in this document

**ABS** Australian Bureau of Statistics

**ACD** Association for Children with Disability

**ATDC** Alcohol, Tobacco and other Drugs Council of Tasmania

**ATOD** Alcohol, Tobacco and Other Drugs

**CALD** Culturally and Linguistically Diverse

**CHFA** Consumer Health Forum Australia

**CRPD** Convention on the Rights of Persons with Disability

**DPO** Disabled Persons Organisation

**DSO** Disability Support Organisation

**FaHCSIA** Department of Families, Housing, Community Services and Indigenous Affairs

**ILC** Information, Linkages and Capacity Building Framework

**IYDP** International Year of Disabled People

**MDAC** Ministerial Disability Advisory Council

**NDAF** National Disability Advocacy Framework

**NDAP** National Disability Advocacy Program

**NDIA** National Disability Insurance Agency

**NDIS** National Disability Insurance Scheme

**NDS** National Disability Strategy

**PDAC** Premier's Disability Advisory Council

**PWDA** People with Disability Australia

**PWDACT** People with Disability ACT

**PWDWA** People with Disability WA

**SARC** Social Action and Research Centre, Anglicare Tasmania

**TDERL** Tasmanian Disability Education Reform Lobby

**TDL** Tasmanian Disability Lobby

**TWD** Tasmanians with Disabilities

**TUHSL** Tasmanian Users' Health and Support League

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# Executive Summary

Tasmania currently lacks a strong collective disability voice. There is a consensus that this has been the case for a number of years and that it leaves a significant gap. Filling this gap is imperative, particularly at a time of major reform in disability services when hearing the voice of people with disability is crucial in order to guide change and reform and to safeguard the rights of all people with disability.

This paper is the result of discussions with over 30 stakeholders in both Tasmania and other jurisdictions during January and February 2016. It explores what mechanisms currently exist to hear the voice of people with disability, what gaps this leaves and how Tasmania might move towards strengthening the disability voice in the state. The discussion paper identifies:

- *a diversity of voices in the Tasmanian disability sector facilitated by a range of different organisations;*
- *policy frameworks which prioritise and facilitate hearing the voice of people with disability to ensure that it is not seen as an optional extra;*
- *a period of extensive disability reform which puts people with disability and their choices centre stage, imperative to have their input in decisions about their own care but also about policy and service design and delivery;*
- *a wealth of experience from other jurisdictions and sectors about strengthening the disability and consumer voice;*
- *concerns across Australia about government commitment to and funding for systemic advocacy and representation for people with disability; and*
- *a lack of a strong collective voice in Tasmania controlled by people with disability.*

**The discussion paper proposes three potential options as a way forwards. They are:**

## **1. A disability voice working group**

A small group of invited participants operating with terms of reference and a broad outlook to explore models, recommend options, agree process and function and develop a strategic plan. A neutral chair would be advantageous.

## **2. A broader consultation**

A workshop with invited participants across the state who can make a worthwhile contribution, generate ideas and issues, galvanise collective action and make decisions. This would serve to act as a developmental process across the sector and incorporate the views of a broad spectrum of people with disability. Again a neutral chair would be advantageous.

## **3. Government tender**

A government tender for a representative disability voice which can meet specified criteria.

# 1. Introduction

For a number of years people with disability, advocacy organisations, service providers and government have identified the absence of a strong disability voice in Tasmania as a significant gap. Numerous budget submissions from a range of different organisations have asked for funding to develop a well-resourced disabled people's organisation (DPO) to actively represent the interests of Tasmanians with disability.

This gap is part of a broader picture where there has been an absence of any health or human services consumer peak in the state. Little has changed since a review of DHHS funded peaks<sup>1</sup> which noted the absence of a '*body which has the capacity to represent the voice of [health and human services] consumers in a strategic, considered and well researched way*' in Tasmania.

This is an opportune time to be examining this gap and what it means. With the implementation of NDIS and major changes in the provision of disability services it becomes imperative that people with disability who use these services and those who do not are represented in policy development, service design and evaluation, quality improvement and future planning. This requires a disability voice which is not only well-organised and well represented but which is also able to capitalise on capacity building opportunities and respond to the obligations of government to facilitate and support such a voice.

## Aims and methods

This Discussion Paper examines the strength of the current disability voice in Tasmania. It aims to provide a platform from which to have an informed debate about how to strengthen disability voice in the state. In particular the paper:

- *maps current mechanisms for hearing the disability voice in Tasmania, in other jurisdictions and nationally;*
- *explores the opportunities and challenges in ensuring the disability voice is heard;*
- *reviews what the implementation of NDIS means for promoting and supporting disability voice; and*
- *identifies key options and opportunities for Tasmania to strengthen the disability voice.*

The Paper is the result of consultations with over 30 key stakeholders in Tasmania and in other jurisdictions. Informants include people with disability, parents and carers, disabled people's organisations, advocacy organisations, service providers, the NDIA and government.

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<sup>1</sup> Department of Health and Human Services 2008, *Review of Tasmanian DHHS funded peak bodies*, Office for the Community Sector, Hobart.

It also draws on previous SARC work which has examined the development of consumer voice in other sectors and draws out the lessons from this in developing disability voice<sup>2</sup>.

## Definitions and language

The focus of this paper is how to strengthen the authentic disability voice which can speak for, of, with and on behalf of people with disability. In a number of jurisdictions this has been achieved through DPOs. A DPO is an organisation of and for people with disability embedded in a human rights framework and governed and run by people with disability for people with disability. DPOs engage in representation, advocacy and support for, with and by people with disability. They have been seen as critical in acting as a springboard for wider participation by supporting leadership and capacity building of grass roots groups and working to co-produce services and service systems with government and other stakeholders.

Disability advocacy enables people with disability to participate in decision making processes that safeguard and advance their human rights. DPOs may engage in a mix of individual and systemic advocacy. Approaches to disability advocacy can be categorised into six broad models<sup>3</sup>:

- **Citizen advocacy** matches people with disability with volunteers.
- **Family advocacy** helps parents and family members advocate on behalf of the person with disability for a particular issue.
- **Individual advocacy** supports people with disability to exercise their rights through one-to-one support, through a third party or on a group basis.
- **Legal advocacy** upholds the rights and interests of individual people with disability by addressing the legal aspects of discrimination, abuse and neglect.
- **Self advocacy** supports people with disability to advocate for themselves or as a group.
- **Systemic advocacy** seeks to introduce and influence longer term changes which remove barriers and address discrimination to ensure the rights of people with disability are attained and upheld to positively affect the quality of their lives.

There is a move from using the language of participation and involvement to the language of partnerships, co-production and co-design.

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<sup>2</sup> See Hinton, T 2009, *Strengthening the mental health consumer voice in Tasmania*, Social Action and Research Centre, Anglicare Tasmania and Hinton, T 2010, *Voices on choices: Working towards consumer-led alcohol and drug treatment*, Social Action and Research Centre, Anglicare Tasmania.

<sup>3</sup> Australian Government 2014, *Operational guidelines for the National Disability Advocacy Program (NDAP)*.



## 2. What Does the Disability Voice Look Like in Tasmania?

The population of Tasmania may be small but the incidence of disability is high. According to ABS figures<sup>4</sup> there are 113,000 people or 23% of the population in Tasmania who report limitation, restriction or impairment which has lasted or is likely to last for at least 6 months and restricts everyday activities. Actual figures are likely to be higher. Over 60% of people with disabilities are under 65 years, but a higher incidence of disability is expected among older people who acquire disability as they age. As Tasmania has a larger population of older people, this makes people with disability a higher proportion of the population than in other states.

These numbers, approaching a quarter of the Tasmanian population living with a disability, are not insignificant. It means that a strong disability voice is a priority for Tasmania so that people with disability can have in say in those issues which impact on their lives.

### Mechanisms to hear the disability voice

There are currently a diverse number of ways to hear the disability voice in Tasmania.

#### Advocacy organisations

There are three advocacy organisations in Tasmania which work specifically in the disability area. They are funded by the State and through NDAP to provide individual advocacy to people with disability, their families and carers. They also receive varying amounts of funding to undertake systemic work about broader issues which are identified through advocating for individuals.

#### *The Association for Children with Disability*

The Association for Children with Disability (ACD) is a membership organisation with a Board where the majority of members are parents of children with disability and the vision is 'parents empower parents'. ACD has fostered a strong parent/carers lobby in the state where systemic advocacy is based on the issues which arise through their consumer base. They have well-developed partnerships with other advocacy organisations and specialist disability services and regular communications with government to press for change.

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<sup>4</sup> Department of Premier and Cabinet 2013, *Disability Framework for Action 2013-2017* – from ABS, *Disability, Ageing and Carers, Australia 2009, State tables for Tasmania*.

### *SpeakOut*

SpeakOut is a membership organisation for people with intellectual disability with a network of self-advocacy groups across the state. The annual conference provides a platform for identifying and prioritising issues for systemic advocacy work and builds on the local evidence base of individual advocacy to identify trends and build solutions. However only a small part of their funding is specific to systemic advocacy work and represents less than 2% of their overall budget. Yet there is a general consensus that they are able to punch above their weight and that they have been successful in raising issues which impact on people with intellectual disability in the state.

### *Advocacy Tasmania*

Advocacy Tasmania provides individual advocacy across a number of sectors including mental health, disability and the alcohol and drug treatment sector. Five percent of funding is for systemic advocacy work, again driven by the evidence base from individual advocacy.

Advocacy organisations report a recent renewed interest in what they have to say about the experiences of people with disability from government and from the service sector. Again, in the absence of a disability peak they report an expanding role in becoming a central focus for information about the consumer experience alongside strong consumer voice mechanisms. Regular quarterly reporting mechanisms have been established with NDIA about systemic issues and their resolution. However they also report a potential for expansion in the systemic advocacy work, but a lack of resources to support it.

### **Disability-specific organisations**

Tasmania has a diversity of disability-specific organisations which promote the interests of people with particular kinds of disability and which have grown up in an ad hoc way across the state. Their main function is to support their membership through facilitating support groups, social and recreational activities and information alongside individual advocacy work. In some instances they can provide limited assistance with disability related expenses or help with specialist equipment.

A number of these groups receive funding from the State through Disability and Community Services to provide information, referral and case management services but not systemic advocacy. Funding however is limited and they may or may not have paid workers or office premises and have varying levels of reliance on fundraising. Some are able to operate more like peak bodies and will get involved in systemic advocacy work, usually on a reactive basis through lobbying and campaigning, awareness raising and participating in practitioner training programs.

Although some are linked into national strategies, bodies and agendas and look to the national peaks for their agendas, many do not. Despite an awareness that there is a need to strengthen systemic work and to educate their own membership about these issues, there

is limited financial support for this and they compete with each other for what funding may be available.

### **Government advisory structures**

There are two bodies with representation from people with disability that advise government on disability issues.

The Premier's Disability Advisory Council (PDAC) has representation from both people with disability and families and carers. Chaired by the Premier, its key role is to operate as an accountability framework around the implementation of the National Disability Strategy. It provides strategic advice to government on directions, policies and solutions and helps to monitor the roll out of Tasmania's whole-of-government disability policy and the Disability Framework for Action<sup>5</sup>.

PDAC meets four times a year and prepares an annual report to Cabinet about progress in implementation, examples of good practice and recommendations for future actions. Heads of agencies attend the meetings. PDAC has been able to put issues on the table and individuals have sought membership as a position of influence in order to raise concerns. There have also been initiatives to build the skills and capacity of members to represent others.

The Ministerial Disability Advisory Committee (MDAC) was set up in 2007 to provide independent advice directly to the Minister for Human Services on issues affecting people with disability who use specialist disability services, their families and carers. As well as people with disability, their families and carers, membership also includes service providers. MDAC is seen as a sub-committee of PDAC along with the Sport and Recreation Committee, which advises on the provision of sport and recreation opportunities for people with disability. MDAC meets four times a year, the Chair attends PDAC meetings and regional community forums are held to ensure that advice to the Minister is informed by on-the-ground experience.

Members of both advisory bodies are ministerial appointments selected through an application process and nominations. This means that the agenda is defined by government and membership is not necessarily representative of the spectrum of disability or more marginalised groups, for instance people with intellectual disability. Nevertheless, in the absence of a disability peak, PDAC and MDAC have been seen as a key mechanism for hearing the disability voice.

As the state passes responsibility for specialist services to NDIA, the future of MDAC is unclear. Whatever the outcome there will still need to be a clear disability voice around specialist disability services.

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<sup>5</sup> Department of Premier and Cabinet 2013, *Disability Framework for Action 2013-17*, Tasmanian Government.

## Lobbies

Coalescing around a particular issue with the intention of achieving a specific goal is one way of making the disability voice visible. There have been two recent lobbies in Tasmania.

The Tasmanian Disability Lobby (TDL) was established in 2011 as a campaign to highlight the voices of people with disability, their families and carers in response to what was seen as a lack of accountability or transparency about what was impacting on people with disability in Tasmania. Its main goal was to provide evidence for the need for social and economic reform and to bring NDIS to Tasmania as a mechanism for achieving this. The lobby used social media and a Facebook page to develop a collective voice around these issues. It attracted a strong following of over 2,000 people, collated a pool of opinions and ideas about NDIS and provided a tool with which to inform a number of submissions including changes to the Tasmanian Disability Services Act. The Lobby no longer exists. However, the next step was seen as establishing a disability services commissioner in the state.

The Tasmanian Disability Education Reform Lobby (TDERL) was established in 2012 by a parent of autistic children who had struggled to get the educational support her children needed in Tasmanian schools. She highlighted the absence of a parent voice in this area and of good quality information about students with disability in the education system. TDERL was launched to fill these gaps and advocate for systemic change and for a review of the system which would incorporate the views of parents. Since then data has been collected through an annual parent satisfaction survey as a platform to build a discussion. In 2015 this included a partnership with the Australian Education Union to include the voice of teachers in the debate. The Lobby has a website and provides parents with information about the rights of students with disability so that they are able to advocate for their children. Prior to the last election it also provided an online mechanism for parents to talk directly to politicians about education issues.

The lobby has been self funded and operates through a network of parent volunteers. Funding has not been sought because of the desire to remain 'fiercely independent' and not to acquire any governance responsibilities. TDERL has been successful in moving the discussion away from the needs of those on the severe disability register to the broader spectrum of students with disability and in pushing for a review of the system. It has established good working relationships with government and the media and its views are now sought. The review took place in 2014 and resulted in a number of recommendations about reforming the system for students with disability<sup>6</sup>. It is intended to continue the work which will now focus on monitoring the implementation of the recommendations from the review. It will also continue with the annual parent survey to hold policy to account and see whether policy changes are making a difference on the ground.

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<sup>6</sup> Tasmanian Government 2015, *Improved support for students with disability*, Ministerial Taskforce Report, Minister for Education and Training, Hobart.

## **Individual voices**

There are a number of strong, active and influential disability voices participating in consultative mechanisms and forums and pushing for a stronger disability voice. They may work independently or attached to particular organisations and operate with high levels of expertise and credibility with service providers and government. They may be 'tapped on the shoulder' to input into consultation mechanisms and/or to provide a disability voice in the development and design of policy and service provision frameworks. Some of these voices come from national DPOs which have their secretariat in Tasmania and who work with particular cohorts of people with disability or with particular issues. At times Government has used them as advisory mechanisms and in some cases relied on them for input about sub-groups in the disability population in Tasmania on a voluntary basis. These organisations would like to see state government funding made available to support their participation in these initiatives.

Some of these individual voices have had access to the Australian Government's Leaders for Tomorrow Program. This was an individual leadership development program funded by FaHCSIA to develop the leadership capacity of people with disability. It targeted those who aspired to be leaders or to further develop their current leadership capacity.

Input from individuals may occur in the absence of liaison with other people with disability or with reference to the broader context. They can also be seen as the 'squeaky wheel' and there have been times when 'big personalities' have been in public conflict with each other or have not been seen as representative. There are increasing concerns that those who have been active in this space - 'the old warriors' - are now ageing and leadership in the younger generation to fill the gap they leave is not necessarily visible.

## **Tasmanians with Disability (TwD)**

Until recently TwD was considered to be the only Disabled People's Organisation (DPO) in Tasmania and was regarded by some as holding the status of a disability peak. It had a long and honourable history as an activist organisation which was instrumental in promoting reform in the disability sector and providing strong advocacy and a loud voice about disability issues throughout the 1990s. Over the years there have been attempts to expand the work of TwD as a key policy advocacy body directly accountable to its members living with disability.

However the ability of the organisation to be a cross-disability mechanism for the voice of people with disability able to shape public policy or progress the rights of people with disability was curtailed by long-term underfunding and an ageing membership. This has meant a limited ability to participate in consultation processes and to lead strong collective action. The organisation has now been defunded.

## The broader context

### National Disability Insurance Scheme (NDIS)

The implementation of NDIS through the National Disability Insurance Agency (NDIA) marks a major reform of the disability service sector which puts choice and control for people with disability at its centre. This has a number of implications for the development and impact of the collective disability voice (see **NDIS and the Collective Voice**).

### National Disability Services

Tasmania has a strong disability service sector voice through National Disability Services, the peak body for disability service providers in the state. National Disability Services is connected to the national sector voice and engages in systemic level advocacy to progress the social and economic participation of people with disability. They see consumer engagement as a key component of ensuring good quality services and supports and encourage their membership and the workforce to invest in consumer engagement mechanisms. They try to ensure that their own work reflects the consumer voice by engaging with advocacy organisations to facilitate consultations with consumers on their behalf.

Although their work is founded on the principal that they cannot speak on behalf of people with disability, given the absence of a strong disability voice in the state they have sometimes been seen to be representing and providing a pathway for that voice by default.

### Complaints mechanisms

Complaints about services can, in the first instance, be taken to individual service providers in accordance with their complaints management processes. If they are not resolved at this point complainants using DHHS funded services can pursue their complaint through Disability and Community Services area offices where the complaint will be investigated<sup>7</sup>. If necessary the complaint can be referred upwards to the Director of Disability and Community Services. As these services transition to NDIS, complaints can be pursued through NDIA complaints mechanisms.

Complaints which remain unresolved can also be taken to the Ombudsman. However disability is only one of the Ombudsman's areas and beyond conducting a preliminary enquiry the office has independence over whether or not to take a case on. The Health Commissioner is also limited in what can be done with disability issues.

This means that currently there is no authority specifically dealing with complaints from people with disability in Tasmania. In the absence of this authority, approaching half of the

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<sup>7</sup> Department of Health and Human Services, *Disability and Community Services Compliments and Complaints Procedure*, Tasmanian Government.

complaints brought to the Anti-Discrimination Commissioner are about disability matters. However most of these are about individual difficulties where the complainant is not seeking visibility or broader redress. Energy is required to pursue individual complaints, an energy many with disability do not have.

Many consider that a disability services commissioner with the power of investigation is crucial to safeguarding within the NDIS and to ensure its accountability. Government responded to recent lobbying for a disability complaints commissioner by saying this role is picked up through disability services legislation under the Quality and Safety Framework. In addition there are no resources available to establish such a position. This raises a series of questions about who does regulate the disability industry.

There is also the question of how far a complaints model is realistic in a small community like Tasmania where people may be reluctant to complain publically as they continue to be consumers of services.

### **Development of a health consumer peak**

Tasmania is the only state which does not have a health consumer peak body. The Primary Health Network in Tasmania has contracted the Consumer Health Forum Australia (CHFA) to explore the need and opportunity for establishing a consumer health peak body in the state. This has led to consultations with key stakeholders across Tasmania, the development of a discussion paper and a workshop to explore how to take it forwards. The workshop will discuss the development of a values statement and purpose and start preliminary discussions about the governance of any consumer peak.

At this point there is a consensus that such an organisation is required not to engage in individual advocacy, but to focus on systemic advocacy and ensuring health services listen to consumers and that their design and development is based on consumer feedback and input. A further role would be to provide training for consumers to build their capacity to participate and to be an independent and well informed voice. Potentially any organisation would also be involved in changing the culture around the engagement of consumers whilst assisting other organisations to establish better consumer engagement mechanisms. It is anticipated that it would be an incorporated organisation with a skills based board and a membership base of organisations – those supporting people with chronic conditions. There may be the possibility of initial auspicing from CHFA until it could operate independently. There is a recognition that funding will be limited so the organisation needs to have a well identified purpose and role.

Given the current existence of a mental health consumer peak, Flourish, and the potential development of a stronger disability voice mechanism, any health consumer peak would be working in partnership with these structures. They may be able to share infrastructure and to work jointly around particular health-related issues in policy and advocacy work where there are commonalities. There might also be possibilities for integration into a broader

health consumer organisation, for instance a coalition. This could require some exploration when it comes to the specifics of governance.

### **Tasmanian Government Framework for Community Engagement**

The Framework was developed and introduced in 2013 by Department of Premier and Cabinet to provide guidelines for Tasmanian Government agencies to undertake community engagement<sup>8</sup>. It promotes the importance of community engagement in effective government decision-making and resource allocation and provides tools and resources to ensure engagement by government with individuals and communities.

Potentially the framework provides an avenue for public participation in policy development and service delivery including consultation with the disability community. There are however no specific references to working with people with disability within the Framework.

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<sup>8</sup> Department of Premier and Cabinet 2013, *Tasmanian Government Framework for Community Engagement*, Tasmanian Government.



## In summary

### What we have:

- a rich diversity of voices
- well established advocacy and other organisations facilitating the disability voice
- a recently defunded disabled people's organisation which has found it difficult to lead strong collective action
- a perception that there are too many disability voices and that enough resources are already invested in this area
- difficulties in imagining how a collective disability voice might be strengthened
- a competitive funding environment where agencies feel threatened and are protective of programs and services

### What we don't have:

- a strong collective cross-disability voice. This absence has been a feature of the Tasmanian environment for a number of years
- a disability or health and human services sector peak which is able to promote and support the growth of a stronger disability voice
- a commitment to the obligations of government to have mechanisms in place to hear disability voice beyond involvement in advisory bodies

### 3. The Policy Framework

There are a number of key rights, policy and strategic frameworks which serve to specify how the voice of people with disability will be heard in Australia. These function to ensure that hearing the disability voice is not an optional extra but rather imperative to securing the rights of people with disability and their involvement in decisions which affect them.

#### The Convention on the Rights of Persons with Disability (CRPD)

Australia is a signatory to the Convention which was ratified in 2008. Under the Convention there is a general obligation *to consult with and actively involve people with disability, including children, in the development and implementation of legislation and policies to implement the Convention and in other decision making processes concerning issues relating to persons with disability, through their representative organisations*. CRPD is unique in being both a human rights instrument and a development instrument which aims to redress the disadvantage faced by people with disability and afford them the same rights as all other Australians.

Ratifying the Convention means that the involvement of people with disability in issues which affect them is a right and Australian governments have a responsibility to actively support and fund the establishment of structures to support that right so that disability specific and mainstream policies and services are informed by people with disability, their families and carers.

Australia is also signatory to a number of other international human rights treaties which have specific obligations around people with disability and their engagement, representation and participation. These include the Convention on the Elimination of all forms of Discrimination Against Women, Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, International Covenant on Civil and Political Rights Convention, International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of the Child.

A review of Australian Governments by the United Nations in 2013 and their implementation of CRPD reported some gaps in effective engagement mechanisms with disabled people's organisations and a poor commitment to funding and supporting these organisations in some jurisdictions<sup>9</sup>.

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<sup>9</sup> Australian Human Rights Commission 2013, *Australia's Universal Periodic Review, Progress Report*.

## National Disability Strategy 2010-2020 (NDS)

This is the primary vehicle for progressing and monitoring Australian obligations under the CRPD and ensuring that its principles are incorporated into policies and programs. It is a cross-agency, cross-jurisdiction agreement between all federal and state governments about domestic implementation of the CRPD with a 10 year plan to promote the rights and inclusion of people with disability and guide activity across six key domains<sup>10</sup>. These domains are health and wellbeing, economic security, learning and skills development, rights, protection and justice, inclusive and accessible communities and personal and community support.

It is only by acting across the spectrum of government that activity can hope to make a difference to the lives of people with disability. NDS guides government activity across mainstream and disability-specific areas of public policy, drives improved performance of mainstream services and gives visibility to disability issues to ensure they are included in the development and implementation of all public policy that impacts on people with disability.

Each state/territory government has its own implementation plans under the NDS. In Tasmania these plans are driven by the **Disability Framework for Action 2013-17**. This aims to improve participation in social, economic and cultural life through the development of Disability Action Plans by government departments and working collaboratively with community service organisations, government and industry. The Framework is guided by a set of principles about the involvement of people with disability in shaping policy, program development and legislation. Areas for action include:

- *supporting an effective network of community organisations and peaks that provide services and supports;*
- *providing opportunities for people with disability to develop leadership capacity;*
- *meaningfully engaging people with disability in the design of legislation and policy; and*
- *supporting independent advocacy to protect the rights of people with disability.*

The effectiveness of NDS in driving change has been criticised as weak and commentators have asked for stronger accountability frameworks, including annual reporting to Parliaments. In Tasmania implementation of NDS and Disability Action Plans are monitored through PDAC and annual reports to Cabinet.

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<sup>10</sup> Council of Australian Governments 2011, *National Disability Strategy 2010-2020*, Commonwealth of Australia.

## National Disability Advocacy Framework (NDAF)

This outlines a nationally consistent framework for both individual and systemic advocacy and the structure that governments will work within to enable and support people with disability to safeguard their rights and overcome barriers, underpinned by a person-centred approach.

The Framework covers common definitions and desired outcomes and is implemented through the National Disability Advocacy Program (NDAP). Under the Program it is intended that people with disability have access to effective advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights. In 2015 the Australian Government funded 58 organisations under NDAP across Australia to provide this advocacy.

The Framework is currently under review to ensure that it remains relevant in the new NDIS environment and to spell out how advocacy will be provided as the NDIS is rolled out<sup>11</sup>. There is likely to be a big demand for advocacy from those who are navigating the new and complex terrain of NDIS. Recent feedback demonstrates that participants working with an advocate get more comprehensive plans and better outcomes. Effective advocacy so that people with disability can realise their rights within the scheme should be an intrinsic feature of NDIS that is visible, accessible, available whenever required and free both in monetary terms and from conflicts of interest. It requires genuine independence from NDIS so that advocacy organisations do not struggle to bite the hand that feeds them. NDIA staff and organisations are required to proactively identify circumstances where participants could benefit from it and provide information about how to access it.

To this end, in April 2015 the Disability Reform Council agreed that the NDAP will be funded and run independently of NDIS, including supporting systemic advocacy, legal review and representation. However NDIS may provide education, capacity building and decision-making supports as part of individually funded plans or through the Information, Linkages and Capacity Building Framework (see page 20). This means that allocating funding for systemic and individual advocacy and representation will continue under NDAP administered by Department of Social Services and by state governments. However there remain questions about the overlap between supported decision-making and individual advocacy which it is hoped the review will resolve.

This means that to date there are two funding streams for disability voice. The first is through the NDAP which is about providing individual and systemic advocacy but primarily individual advocacy. Then there is state level funding for a representative voice and/or peak organisations.

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<sup>11</sup> Department of Social Services April 2016, *Review of the National Disability Advocacy Program*, Discussion Paper, Australian Government.

## In summary

*Australia has a strong framework to prioritise the voice of people with disability and ensure that they are heard. This includes:*

- The CRDP, NDS and accompanying Disability Action Plans. These require governments to ensure the full involvement of people with disability in the design and delivery of legislation, policy and service systems;*
- The National Disability Advocacy Framework. This puts both individual and systemic advocacy at the heart of safeguarding the rights of people with disability;*
- A decision that advocacy and representation should be funded outside the NDIS; and*
- The further progression of rights to involvement through the NDIS Quality and Safeguarding Framework.*

*Yet there are currently concerns about the monitoring of key policy initiatives and frameworks designed to facilitate the voice of people with disability and the commitment of governments to ensure that they are fully implemented.*

## 4. National Disability Insurance Scheme and the Collective Voice

NDIS provides entitlement-based lifelong care and support to people with disability and is a key plank in implementing the National Disability Strategy. From July 2016 all disability clients and services in Tasmania will transition from government to the NDIA. This represents a fundamental market shift where the government is no longer the customer and where the participant has choice and control about where and how they spend their funding package. Supports which are considered to be 'reasonable and necessary' are largely restricted to those supporting daily personal activities and employment related support, but NDIS also aims to facilitate full social and economic participation and enable choice and control in the pursuit of these goals. For both NDIS and NDS to achieve these objectives people with disability need to be integrally involved at all levels and in all decisions which affect their lives. These include in government, in the NDIA, in provider organisations and in disability representative and advocacy organisations<sup>12</sup>.

### Consumer engagement in NDIA

The implementation of NDIS through the NDIA has embedded consumer engagement mechanisms throughout the working of the agency and there is an ongoing commitment to co-design and to remaining open and transparent.

At a national level and under the NDIS Act 2013 the NDIA have established an Independent Advisory Committee of consumers to provide advice to the NDIA Board in performing their duties. In addition 17% of NDIA staff have a disability, including those operating at senior levels, and 50% have lived experience in some form.

At a local level, although there are few details about how participants will report back about their individual funding packages, participant satisfaction ratings are particularly high in Tasmania. Consultations are held with cohorts of the disability population; for example those with acquired brain injury and with the Indigenous community. Four regional forums were recently conducted, Are You Being Heard, which drew on the community rather than just provider organisations for participation. There is also a commitment to conduct information sessions for consumers through Disability Support Organisations (DSOs) and disability-specific organisations are resourced to conduct consultations with their membership. Most recently there has been work with the Youth Network of Tasmania

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<sup>12</sup> See Goggin, G & Wadiwel, D 2014, 'Australia Disability Reform and Political Participation' in *Australian Review of Public Affairs*, University of Sydney.

(YNOT) about how best to capture the youth disability voice in the state and to develop an appropriate model.

There are two aspects of NDIS which are about ensuring the protection and furtherance of the rights of people with disability – the Quality and Safeguarding Framework and the Information, Linkages and Capacity Building Framework.

## Quality and Safeguarding Framework

This is currently under development and aims to ensure that the NDIS provides good quality supports, maximises choice and control, protects the rights of participants and safeguards them from harm. The primary relationship is now between the individual participant and the provider, so the Framework will replace existing safeguarding arrangements which have been based on funding agreements between governments and providers in a nationally consistent approach. It will apply to all supports funded through NDIS and be designed to assure quality standards in service provision despite their personalised and often intangible nature.

Any safeguarding system in the disability environment cannot operate effectively in the absence of a robust and dynamic advocacy system. The proposed framework and an apparent weakening of the commitment to systemic advocacy and its resourcing have raised a number of concerns in the sector and particularly among DPOs. DPOs and DSOs have a critical role to play in ensuring quality and safeguarding. They are low cost, high value, play an independent role in identifying systemic risks and gaps in services, resolve complex situations across multiple agencies and provide a voice for people with disability in decision making including legislative, policy and program design, implementation and evaluation. DPOs feel that their role in supporting navigation of systems and in building the skills and capacity of people with disability to assert and exercise their legal capacity and rights has been underplayed. Government will still require consultation mechanisms to develop and implement effective policy.

## Information, Linkages and Capacity Building Framework (ILC)

It has always been recognised that the goals of NDIS cannot be achieved through individual funding packages alone and that both individual and community capacity building is required for people with disability to be able to achieve social and economic participation. There are also those with disability who are not eligible for NDIS support but who nevertheless require some level of support to achieve broader participation and inclusion. All people with disability will continue to require improved access to mainstream services, accessible housing and public transport, inclusive education, jobs, participation in community life and freedom from abuse and neglect.

The ILC Framework provides information, referral and capacity building supports not directly tied to the person with an individual support package. It also aims to build partnerships with local communities and mainstream and universal services to improve social and economic participation. It will attract funding of \$132 million at full roll out. There are five activity streams within the Framework where funding will be available. They are:

- *information, linkages and referrals*
- *capacity building for mainstream services*
- *community awareness and capacity building*
- *individual capacity building*
- *local area coordination*

There are also five priority areas for investment in delivery. These include delivery which is specialist and expert, cohort focused, multi-regional, rural and remote and delivery by people with disability for people with disability. It is intended that Local Area Coordination will provide a nationwide foundation for supporting social and economic participation.

It has been estimated that up to four million people with disability will be affected by ILC, which has been identified as 'critical to the sustainability of the NDIS and the quality and culture of the scheme'<sup>13</sup>. It is suggested that the entire NDIS would be wasted if the ILC framework was not implemented effectively. If people with disability cannot get access to mainstream and unfunded supports and services then the NDIS will fail.

A Commissioning Framework has now been published which translates the ILC Framework into action. This gives guidance about how priorities will be set for funding and the expected outcomes and their measurement. This will be followed by a grants program to be released in Tasmania towards the end of 2016.

## Peer support networks

Of significance in growing a disability voice is the recent investment through the NDIS sector development fund to build local peer support groups across jurisdictions. This is being implemented through Disability Support Organisations (DSOs) and is called the Disability Support Organisation Capacity Building Project. DSOs are often DPOs or independent advocacy organisations. This is a three-year program with the goal of developing a network of groups among people with disability, parents and carers to build natural safeguards, capacity and skills, promote self advocacy and share information and experiences about accessing NDIA support and planning processes. Groups will define their own purpose, priorities and agenda and each has access to \$5,000 to establish themselves rather than for ongoing expenses. It is anticipated that groups will find champions among their membership which will allow them to be sustainable in the longer term. Support and

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<sup>13</sup> From Bruce Bonyhady (Chairman of the NDIA) speech 'Reducing the inequality of luck', ASID Annual Conference, Melbourne 2015.



mentoring to DSOs in this process is provided by Purple Orange<sup>14</sup> in South Australia who maintain a peer connect website. They are also involved in the evaluation of the program.

In Tasmania the three advocacy organisations – ACD, Speakout and Advocacy Tasmania – have formed a coalition to oversee and facilitate this process with the goal of developing 20 groups across the state and with Speakout as the lead organisation. There are currently a number of groups developing under this umbrella and pre-existing groups are given the option of transitioning into the program. These groups include those focused specifically on information about access to services and rights within NDIS, groups for particular disabilities or situations and a possible virtual group for parents and carers. Some are becoming friendship groups which may last a lifetime. Others are more information orientated with a membership which comes and goes according to their needs.

The model is flexible, adaptable and sees government investing in people with disability talking to each other without an imposed agenda. It has the potential to build community capacity and resilience, support individuals, problem solve, generate ideas and provide a focus for more collective action and advocacy through sharing experiences. Potentially the groups provide direct access to people with disability beyond provider organisations, at the same time as their links with DPOs or independent advocacy organisations connect them into advocacy support and representative voice.

However, although peer support groups must be taken into account in any discussion about strengthening disability voice, their future as a mechanism for building disability voice is unclear.

## **NDIS and collective disability voice?**

The NDIS has emerged from a drive to ensure that individuals are controllers of their own destiny. Individual voices are now being heard because everyone is involved in their own planning. But what does this mean for a strong collective voice which can constantly challenge government and service providers to do better? Much is currently unknown about the realities of what NDIS will offer and there are complex questions about the interaction between NDIS and other parts of disability social policy<sup>15</sup>. In Tasmania, as elsewhere, there is commonly a poor understanding of the NDIS, and as some informants said ‘we don’t know much about it. It’s in its infancy’. However a number of issues can be raised about its potential impact on the collective voice of people with disability.

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<sup>14</sup> JFA Purple Orange is the social policy agency of the Julia Farr group, which conducts research and engagement in dialogue with people with lived experience of disability to develop policy and practice.

<sup>15</sup> Goggin op. cit.

## The challenges

Firstly how far does NDIS take the pressure off advocating for transformational and structural change? NDIS works with the individual and the individual can be isolated. The holder of a funding package which may include taxi subsidies or who has been provided with an accessible vehicle is less likely to agitate for accessible public transport. The collective voice is being subsumed under the voice of the individual. Many would say that a voice from the outside is required whatever the service system looks like or whatever reforms are being implemented. Yet because NDIS is a program based on individual choice and rights it has introduced a complacency that people are being heard together with a lessening of perceived responsibility from Governments to hear the broader disability voice.

Secondly the NDIS is only for a small population of people with disability and it excludes those who are accessing support in other ways because either they are too old for NDIS or their disability is not severe enough to meet the eligibility criteria of 'lifelong and enduring'. It is anticipated that Tasmania will have about 10,000 individual support packages but with four times this number potentially benefiting from ILC services and with 20-30,000 people entitled to some form of support. In many people's minds NDIS has begun to colonise the disability world. A narrow focus on NDIS and individualised funding and a belief that it has solved all the problems risks a lack of visibility for the rest of the disability landscape, including broader accessibility and inclusion issues and the voices of those who will not benefit from individualised funding. As one stakeholder said:

"NDIS is a hugely positive thing but it will never be a panacea. More than ever there is a tendency to get complacent about disability. But accessible transport or inclusive education won't be delivered through NDIS nor will attitudinal barriers to employment be tackled or issues for over-65s where NDIS is not applicable. Without a strong consumer voice and collective action there will be problems, so to think collective action is not required is very naïve."

Coggin<sup>16</sup> has raised the issue about how far NDIS has a mandate to facilitate the political participation of people with disability alongside promoting social and economic participation. Historically individual and systemic forms of advocacy have been crucial in enabling people with disability to address barriers and discrimination, facilitate access to support and achieve social and political change. There is a case for NDIS to have a role in supporting people with disability to take an equal place as political and civil decision makers. If this is the case, some have argued that NDIS should contribute additional resources for advocacy and especially to assist marginalised groups to have a voice.

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<sup>16</sup> Ibid.

Although both state and Commonwealth governments continue to have a role in funding systemic advocacy there are increasing concerns about their commitment to funding civil society especially when, in reality, there is a tendency to defund groups which are critical of government. With money passing from the state to NDIA will the Tasmanian Government be prepared to fund a peak or systemic advocacy sector in a few years time?

Disability specific organisations which are currently funded by the state for individual advocacy, information, referral and case management work will be seeking funding through ILC for information and capacity building activities and particular projects. This work maps neatly into the ILC framework. But ILC will not be providing operational funding for community based organisations and it also means competitive tendering, which can be divisive, alongside the need to foster choice and control potentially through the existence of small organisations. The loss of small disability specific organisations and the support they provide may be significant and may impact on collective voice in a competitive environment.

Lastly there is an attitude among funders that all aspects of disability support and services will be met through full implementation of NDIS. This makes fundraising and accessing philanthropic support more challenging.

## **Opportunities**

Whilst the NDIS might limit opportunities to develop collective voice, at the same time it may present new opportunities to strengthen and support it.

Firstly the ILC framework will serve to highlight the inadequacies of existing systems – health, housing, education, justice – and how mainstream and universal services are held responsible for the services that they deliver to people with disability. The need for clarity about where the responsibilities of NDIS cease and responsibilities of other services and sectors begin will mean asking questions about, for instance, why NDIS should be funding taxis when the public transport system is not accessible. The same may be true for accessible housing or health services. Potentially this then becomes an opportunity for systemic advocacy and provides a pivotal leverage point to progress reform or for the NDIS to become the lead in systemic advocacy in these areas.

The development of peer support groups through NDIA provides opportunities to build grass roots activity. When people can come together with others to talk about their experiences with services they acquire a greater understanding of broader issues and are then more able and more motivated to acquire collective voice to raise the problems they experience. However building capacity requires a longer term investment than just three years and it is usually not until people strike a problem and are seeking information that they see beyond their own experience, want to have a voice and to be part of collective action. Sharing experiences does not feed into policy or legislative change unless the ability to represent and lead is there. Grass roots activity cannot be the only investment, and there needs to be a focus on how this activity might feed into or nest in a collective voice

structure which has a mandate to speak on behalf of people with disability. This is when capacity building is required to realise rights. At the same time the nature of the DSO coalition in Tasmania which is overseeing development means a focus on parents/carers and those with intellectual disability. Other kinds of disability or those who do not use services are unrepresented

Lastly the ILC framework is currently fluid and it is unclear how the commissioning process and grants program will work. Although it will not provide operational funding it is potentially the new way in which governments will recognise representative voices and how DPOs can demonstrate their usefulness. It is doubtful whether governments will fund a representative voice without any connection to a specific project or the ILC framework. If the NDIS is about choice and control it could be expected that multiple organisations should be involved in building an infrastructure, providing supports, capacity building and linkages. There may be a role for government in encouraging people with disability to form and join disability-led organisations which can represent them at state and national levels<sup>17</sup>. Building capacity to potentially strengthen the collective voice tied to the provision of services may fit into one of the five funding streams and there may be an opportunity for people with disability, advocacy organisations and information providers to reshape and redesign what they do so that it fits within the ILC framework. This is especially the case when one of the priority areas for investment is delivery by people with disability for people with disability.

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<sup>17</sup> Goggin *ibid.*

## In summary

- *Independent voices are critical to ensure the emerging disability market place grows in a way which promotes human rights. Many failures of support systems resulting in human rights violations have only been brought to light by DPOs and independent advocates.*
- *Even when government agencies and complaints bodies are visible and approachable there will remain instances where people are unable or unwilling to make a complaint. Those most impacted by these issues are also the least likely to complain.*
- *The NDIS does not absolve government from its obligations under the CRPD to support and strengthen disability voice and it offers both opportunities and challenges.*
- *There are concerns about the underplaying of the role of DPOs in ensuring quality and safeguarding within the NDIS.*
- *A strong disability voice is crucial at a time of change and reform.*

## 5. Options for Tasmania

Informants described a pressing need for a strong consumer-led disability voice in the state which can provide representation, information, systemic advocacy and build relationships with government. With major reform being implemented and room for new ideas and innovation, this was considered an opportune time to develop a stronger voice and imperative in terms of being able to comment on, contribute to and monitor the implementation of reforms and the impact on people with disability.

### What does the lack of disability voice mean?

It is not enough to say we need a stronger disability voice because we do not have one. There is a need to examine what its absence means and how strengthening it might be of benefit and the contribution it could make. Informants were asked to reflect on the nature of the gap and what it means. They identified that it means:

- *A lack of or no voice for people with disability who are not serviced by the advocacy organisations, for those not eligible for NDIS, for those using mainstream services and for particular cohorts; for example women, CALD and Indigenous people with disability.*
- *People with disability being seen as a homogeneous group who share the same needs and issues rather than recognising diversity.*
- *A celebration of the 'superhero' rather than a more general acceptance of the contribution people with disability can make.*
- *Difficulties in building leadership and a new generation of activists without a base or common cause to galvanise activity. This is accompanied by a complacency that activism is no longer required because we now have the solutions.*
- *Only having a voice if there is a problem rather than a more proactive approach. Opportunities to raise issues can be compromised by the fear individuals may have of losing services.*
- *Government frustration. In the absence of a one-stop-shop, Government tends to cherry pick the loudest voices or listen to those mediated by advocacy organisations and other stakeholder groups as proxies for the disability voice.*
- *The development of policy and services in the absence of disability voice and a general lack of disability awareness in the Tasmanian community.*

A strong, well-resourced disability voice fulfils the right of people with disability to have a direct voice of their own and to be consulted about issues which affect them, not just those which are disability specific. It means that they can be contributors, not just consumers, hold decision makers to account, push for improvements and lead the way in promoting cultural shifts in attitudes. Disability voice can maintain a watching brief to ensure quality and safeguarding mechanisms are in place for the most vulnerable and provide a uniform benefit to the broader community of people with disability, including those not engaged with services or the NDIS.

A stronger voice for people with disability is a strategic investment for Government. It ensures that they are well informed about the opinions, needs and interests of Tasmanians living with disability and can integrate this knowledge into the development of policy and services. It can provide a one-stop-shop for hearing the diversity of voices amongst people with disability and facilitate and mediate consultations and co-design work.

## Tasmanian environment

Any strengthening of the disability voice must be able to take into account Tasmania's unique geographic, social and political environment. This means recognising:

- *Difficulties inherent in bringing people together when they are isolated, dispersed, poor and may be suspicious of the motivations of organisations. This presents challenges in sharing experiences across regional cultures in a fragmented disability community.*
- *The history of consumer development and participation mechanisms in the state with a combination of high expectations, under resourcing, lack of clarity about roles and pessimism in some quarters about the capacity and/or sustainability of consumer mechanisms and organisations generally.*
- *A strong disability services and advocacy sector resourced to work with particular cohorts of people with disability and parents/carers, and an older generation of disability activists who are ageing with few younger people growing into leadership roles.*
- *A small community with few resources and pressure to combine a number of functions into one organisational structure. This can result in good outcomes like efficiencies and cost effectiveness but it can also mean inbuilt structural conflicts.*
- *The potential emergence of a health consumer peak and what this means for priorities, collaboration and resourcing for disability voice.*

## Key messages from other jurisdictions and sectors

Informants gave an overview of the 'who, what and how' of strengthening the disability or consumer voice in their jurisdiction or sector (see Appendix). What is clear is that although there are common patterns and themes, every jurisdiction and every sector has a different story to tell. All have struggled and found that establishing an effective model is hard and can take a long time. This means that despite a temptation to seek an instructional 'how to' manual or to emulate others there is no one model which fits all circumstances. Rather lessons learnt elsewhere can be used to develop a Tasmanian approach to strengthening disability voice.

These lessons indicate that the critical success factors for a strong disability presence in Tasmania are:

### Who?

- **Leadership**, a body of people who are skilled, have capacity, who want to be involved and are prepared to do extra work. This may involve a journey from anger to communicating effectively and utilising a collective approach. Dominating leaders can disempower others leading to factions and breakdown.
- **Capacity building**, training and mentoring to build skills. Auspicing can be a useful development tool as long as the mutual requirements are clear.
- A willingness to get **support from people who do not have a disability** but who have the required skills. Committing to only working with people with disability can mean recruiting from a small pool.

### What?

- A need to **keep it simple** with an emphasis on what you can do for others rather than vice versa. It is critical to offer a tangible product which is of direct relevance to the lives of people with disability.
- **Getting the fundamentals right** – the philosophy which sits underneath – so that all involved have the same aims and can embrace both difference and common purpose.
- **Clarity about purpose**. Alongside building and providing a voice, what other services will be offered – individual advocacy, support and recreational activities, education and awareness raising, information and consultancy, project work and assisting government.
- **Dealing with diversity**. Avoiding competition between different cohorts and reaching agreement about how to work together.

### How?

- Developing effective consumer voice can be **a fragmented, stop/start process** and a long-term journey which may take several years.
- **Solid foundations** with an organisational base and supportive infrastructure – for example from a peak, an advocacy or other organisation.
- **Adequate resourcing** to develop a professional and credible service and build productive working relationships with all stakeholders.
- **Setting priorities** and thinking in project sized pieces to avoid the pressure of high expectations and trying to do everything at once. It needs to be well planned, start small and build up gradually using a staged approach and a road map.



## Envisioning the disability voice

Informants were asked whether they had a vision for disability voice in Tasmania, what it would look like and what purpose it would serve. There was a consensus about what is required and the fundamentals of any such disability voice. It should be able to:

- *Provide a cross-disability voice which is mandated and recognised by people with disability, their family and carers, service providers and government as representative of Tasmanians with disability.*
- *Promote the rights of all people with disability to be involved in national and state policy planning and service development which affects them and their lives, and the responsibility of government to fund, support, listen and collaborate.*
- *Operate effective consultation mechanisms with its membership and the broader community of people with disability to seek consumer views.*
- *Offer a vision about how things should be, a mission about how to get there and capacity to build leadership.*
- *Provide a watchdog for people with disability to ensure that the development of services and reform processes enhance their capacity to participate in social, economic and political processes.*
- *Work in collaboration with parents and carers in matters of joint interest.*
- *Develop a marketing strategy to publicise, promote and put disability on the map in Tasmania and raise public awareness about disability issues.*

## Options

What kind of model might fulfil the vision as articulated above? A number of informants voiced the view that other options apart from a constitutional organisation with a membership should be considered, at least as a starting point.

1. **A new disability consumer peak organisation.** *This was described as a cross-disability disabled people's organisation run by and for people with disability and founded on a rights based perspective. The organisation would be membership based and governed by a Board or Committee of Management. It would be well resourced with recurrent not project funding and adequately staffed. Representation and systemic advocacy would be its key purpose but it would also provide information about disability rights, capacity building, education and awareness raising. There would be the ability to operate as a peak for smaller disability specific organisations and to build collaborations and partnerships with parents, carers and advocacy organisations.*
2. **A branch of a national peak,** *for example PWDA or the Cross-Disability Alliance. This offers advantages as a state-based chapter of a powerful cross-disability national network and the support and mentoring this could provide. The starting point would be a funded branch coordinator to build visibility and membership. It offers the possibility of adding specific funded posts to cover particular cohorts of people with disability; for example women. Questions were raised about the*

capacity of national organisations to mentor a state-based branch without additional resourcing.

3. **An independent executive role** attached to the current advocacy groups to act as a central focal point for collating information and feeding it through. This was seen as a preliminary stage in exploring what is required prior to further developments but it would have the ability and mandate to operate like a peak body. Questions were raised about ownership and the ability of advocacy organisations to grow disability voice.
4. **A community development approach** which can build on the current NDIA peer support initiative. This brings people together to share experiences and anticipates the emergence of champions or leaders who can promote the sustainability of groups. The initiative has the potential to grow a more collective voice which can speak to government from the ground and from where people live, work and play. In the longer term this may result in growing a new generation of activists. It might also incorporate the need for targeted work to build a youth network. However given the significance of the current absence of a strong voice and the long term nature of capacity building, this approach would be better served by nesting in a broader overall structure for disability voice which can be proactive.
5. **An issue-based approach** where people with disability rally around a single significant issue and galvanise action; for example accessible transport or NDIS. A successful example of this is TDERL which in the education sector has been able to garner the parent voice and monitor the impact of policy through providing an evidence base. Here there is potential to gather extensive expertise in one particular area and to employ social media as a powerful tool for collective action. However there are also limitations in not covering the range of issues which are impacting on people with disability and not being able to set a more pro-active agenda.

The above models are not necessarily stand-alone solutions. There may be ways in which different models can be combined to provide the most appropriate response for Tasmania.

## Where next?

Given a range of options, what are the next steps? Informants agreed that further discussions were required in order to agree fundamentals, gather support and debate practicalities. They also agreed that any further discussions will need to be guided by and incorporate:

- *The courage to make difficult decisions. If it was simple to strengthen disability voice it would already have occurred.*
- *Avoiding talkfests and creating something we already have.*
- *A neutral chair/facilitator who can operate as an 'honest broker'.*
- *The involvement of government from the beginning of the process.*
- *An acknowledgement of the strong history of disability voice in the state and the foundations on which any new structures are being built.*
- *A recognition of the need to build capacity and skills in leadership and representation.*
- *Careful consideration of a role/network for young people and what this might look like.*
- *An exploration of funding opportunities via:*
  - *seed funding by government to meet their obligations to listen and take account of those with lived experience*
  - *the ILC framework in relation to building capacity, sharing and exchanging information and meeting NDIS information needs*
  - *NAPF support for systemic advocacy services on an ongoing basis.*

Options for the next steps are:

1. **A disability voice working group.** *A small group of invited participants operating with terms of reference and a broad outlook to explore models, recommend options, agree process and function and develop a strategic plan. A neutral chair would be advantageous.*
2. **A broader consultation** *or workshop with invited participants across the state who can make a worthwhile contribution, generate ideas and issues, galvanise collective action and make decisions. This would serve to act as a developmental process across the sector and incorporate the views of a broad spectrum of people with disability. Again a neutral chair would be advantageous.*
3. **Government tender** *for a representative disability voice which can meet specified criteria. This was the model used to redesign disability voice at a national level.*

Whatever option is chosen it will require building the model publically and in an inclusive and transparent manner.

# Appendix: Disability and Consumer Voice Elsewhere

What does disability voice look like elsewhere? Key informants nationally and in four different jurisdictions were identified to describe the health of the disability rights movement in their area, its growth, development, role and sustainability. This has been combined with information about consumer voice in the mental health, alcohol and drug and housing/homelessness sectors in Tasmania to see what can be learnt from these experiences about developing the Tasmanian disability voice.

## National

At a national level disability voice has recently been reconfigured through the establishment, in 2015, of new disability peaks to provide a voice for people with disability. They advise government about disability issues and improving the social and economic participation of people with disability. Five organisations have been funded to provide cross-disability systemic advocacy and representation, information and advice, research and education. They are:

- *Australian Cross Disability Alliance. This consists of four disabled people's organisations – People with Disability Australia, Women with Disability Australia, First Peoples Disability Network Australia and National Ethnic Disability Alliance. They work collaboratively under the umbrella of an alliance with shared priorities, issues and concerns.*
- *Children with Disability Australia. They replace a disability peak environment based on an ever-expanding diagnostic model which was not sustainable and are the result of many years of reviews and recommendations about disability voice at a national level. Concerns have been expressed about the restructuring and the consequent defunding of many organisations working on behalf of specific sections of the disability community<sup>18</sup>. In particular there are concerns about the loss of specialist knowledge and networks and what this might mean for the successful implementation of NDIS and NDS.*

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<sup>18</sup> JFA Purple Orange 2016, *The survival of people-with-disability organisations: Why it is important to sustainably fund diverse peak advocacy organisations in Australia*, Julia Farr Association Inc.

There is also the national peak for service providers – National Disability Services and the Disability and Carers Industry Advisory Council established in 2014. This brings together industry, services, peaks, people with disability and carers at six monthly intervals as a formal mechanism to provide advice and feedback to government about key reform agendas.

## States and Territories

The majority of Australian jurisdictions, like Tasmania, have a diversity of diagnostic-specific and advocacy organisations involved in individual advocacy work. However, unlike Tasmania (and excluding Northern Territory and South Australia), they have also funded disabled people's organisations which have followed similar developmental journeys.

Typically they have started with a small group of committed and passionate individuals motivated by a central goal; for example setting up a disability information resource. Many have worked in a voluntary capacity for years through the efforts of committee members while gradually progressing to becoming incorporated organisations, building a membership and acquiring funding for employing staff and office space. They offer a mix of representation, systemic advocacy, individual advocacy, peer support, education work and information provision.

Different jurisdictions have different infrastructures which have assisted in building disabled people's organisations and their activities. This might include consumer participation frameworks and health consumer peaks which can support and build consumer leadership and offer training and mentoring opportunities. There are also varying commitments from state government to fund the systemic advocacy work being carried out by DPOs.

## ACT

People with Disabilities ACT (PWDACT) began in 1981 during IYDP as a branch of Disabled People International Australia. Four committed people established a committee to set up a representative cross disability advocacy group in the ACT. Like most organisations they started out with nothing more than people and then gradually acquired office premises and small grants which allowed them to employ staff and build a membership. Its mission is to 'represent, promote and support the collective interests of people with

disability and work to bring about an inclusive society'. Total funding is approximately \$68,000 per annum and they now receive funding from the ACT Government for an Executive Officer and administration position. Although PWDACT is a cross-disability DPO, the focus has been more on physical and sensory disability rather than intellectual disability. Instead the voice of people with intellectual disability is taken up by Advocacy for Inclusion which runs self advocacy training across the ACT.

PWDACT has never been a service provider but provides information and systemic advocacy only. To a certain extent this has created problems for them, and as they said it's like '*sustaining yourself on a diet of carbohydrates only*'. They compile a monthly newsletter, conduct regular meetings with stakeholders, undertake systemic advocacy projects and bring a disability perspective to consultations. They also conduct an annual evidence based project which this year is about access issues.

### **New South Wales (NSW)**

NSW has a strong disability voice through People with Disability Australia (PWDA). Although the origins of PWDA, are debated they lie in 1980 when a group of people got together to provide people with disability in NSW with a voice of their own. In 1982 the group became the Handicapped Persons Alliance based on a trade union model and operating a Disabled People's Resource Centre. By 1991 they assumed the name People with Disabilities (NSW) Inc. In 2002 they repositioned as PWDA, a national disability rights and advocacy organisation able to undertake work on national policy issues

Today PWDA is the only cross-disability organisation in the state and receives funding from the NSW Government and from NDAP to act as a cross disability peak and to provide individual and systemic advocacy around policy issues relevant to NSW. It is also funded under the National Secretariat Program in DSS as a national peak and now has a membership of over 2,000 people with disability and 20 organisational members. It has always seen itself as a disabled people's organisation (DPO) grounded in the disability rights movement nationally and internationally. As well as training, information provision, research, development and advocacy most recently they have become a Disability Support Organisation (DSO) and are developing peer support groups across the state. They are also involved at an international level.

Although they work with DPOs in other jurisdictions and may have agreed MoUs with them, they retain separate identities and it is not a federated system.

## **Queensland**

Queenslanders with Disability Network is a statewide organisation of people with disability for people with disability. It has over 700 members and is a company limited by guarantee. Its origins lie in an approach by government to a group of activists in the late 1990s with an offer of funding to provide feedback and advice on key policy issues. Models were explored and once assured that any structure which was set up would have complete independence from Government, the Network was the result. The first few years saw much development work to build the voice of the network and their participation in policy debate as well as the capacity of people with disability to be involved.

It is funded by the Queensland Government's Department of Communities to provide information, support and referral to individuals and feedback from members to inform government policy and peak bodies as its core functions. This supports a staff team of temporary project based and permanent staff and an office. It also receives funding for specific projects from the department which currently includes work to prepare people with disability and specifically those with intellectual disability for the NDIS. It is also a DSO and receives funding from NDIA to facilitate the development of peer support groups across the state.

## **Western Australia**

PWDWA is the recognised peak consumer disabled people's organisation in WA. Like others, it began in 1980 in order to provide information about services and funding was acquired to establish a disability resource centre. After amalgamation with two other organisations it now has a membership base and staffing of an executive officer, six advocates, a project manager and administrative support. It undertakes individual and systemic advocacy work, project work, has become a DSO through NDIA and is involved in developing peer support networks. The individual advocacy work is seen as an effective base for conducting systemic advocacy.

However PWDWA is not funded to be a peak consumer voice and this has meant a struggle to maintain systemic advocacy. Although

Government will approach them for advice the advocacy work is funded via NDAP and the state government has moved away from supporting systemic advocacy. This has meant that much of the representation and systemic work is undertaken voluntarily by members of the committee of management, all of whom are people with disability. Possible philanthropic sources of funding and the ILC Framework are currently being explored to build the capacity of volunteers to undertake systemic advocacy work.

Despite being seen as a strong disability voice, commentators considered that the disability right movement was less healthy in WA than in other jurisdictions where people with disability were more embedded in decision making structures. One explanation for this was the long history of Local Area Coordination in WA. This was described as playing a part in stifling the consumer voice by working with individuals rather than with communities of people with disability.

## Other sectors

Tasmania has a number of sector-specific strategies and approaches to hearing the consumer voice which might offer useful lessons for developments in the disability sector.

The mental health sector has a longer history of consumer voice than other human services. This has been driven by a strong mental health consumer movement and the early adoption of national standards which require mental health services to promote consumer engagement activities<sup>19</sup>. In Tasmania the Mental Health Council represents the interests of the community mental health sector and provides a public voice for service users and the community service organisations working with them. The Council has been instrumental in fostering a mental health consumer network and in supporting the development of the current consumer organisation, Flourish.

A commitment to pool money from previous consumer participation activities to establish a consumer organisation which could coordinate the consumer voice led to the establishment of Flourish in 2011. Flourish operates statewide with a Board and membership and aims to provide an independent voice for mental

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<sup>19</sup> See Hinton, T 2009, *Strengthening the mental health consumer voice in Tasmania*, Social Action and Research Centre, Anglicare Tasmania.



health consumers, develop effective consultation and participation mechanisms, do systemic advocacy at regional, state and national levels, support the development of a mental health consumer workforce and develop the capacity of consumers to participate. Flourish now has an office staffed by a full time executive officer, a part time policy officer and a finance and administrative officer together with a logo, website and Facebook page. Three regional advisory groups operate as forums for consumers to have direct input into how services are developed and delivered both regionally and state-wide. Members are trained and report on current services and service gaps. There is a peer support network which meets regularly to develop the role of the lived experience in the mental health sector workforce through professional development and personal support. Lastly, Flourish offers a consumer representative service with 24 trained consumers who can input into committees and Boards, undertake consultations, staff training and staff recruitment and take on guest speaking roles. Consumers are reimbursed for their time.

Over the past three years since its inception Flourish has reported a number of challenges. These have included:

- *building a solid and sustainable structure on a small budget;*
- *managing high and often unclear expectations from consumers, government and service providers;*
- *the time and resources involved in building regional advisory groups and getting the model right;*
- *developing cooperative relationships with community mental health services; and*
- *maintaining a balance between lower level widespread engagement and quality engagement involving fewer consumers.*

They have learnt that flexibility is essential in order to provide the space to grow, mellow and change as consumer capacity to engage develops.

In the alcohol and other drugs sector (ATOD) Advocacy Tasmania, in the absence of an ATOD consumer organisation, was funded to develop a sector-wide Consumer Engagement Strategic Framework to ensure consumers had input into the planning, development and delivery of ATOD services. This resulted in the publication of a Guide to Consumer Engagement to support ATOD services with consumer engagement. It also led to a shift to focus on how best to ensure higher level consumer engagement so that consumers have input into systemic issues.

There is now:

- *A part-time consumer engagement officer based with Advocacy Tasmania to lead on implementing a service development plan. The plan prioritises consumer capacity building through training and resourcing, a consumer register and a consumer reference group of people with experience of using ATOD services. The group meets monthly to inform implementation of the plan.*
- *Consultancy and support to service providers through the Alcohol, Tobacco and Other Drugs Council of Tasmania (ATDC) about consumer engagement including the collaborative development of training programs, provision of tools, independent consumer engagement facilitation, advice and information.*
- *The emergence of an incorporated consumer organisation – Tasmanian Users' Health and Support League (TUHSL) with a Board of Management and mentoring from a national organisation, the Australian Injecting and Illicit Drug Users League. TUHSL aims to represent the interests of people who use drugs and maintain a reservoir of peers to ensure services engage in credible consumer participation and to contribute to quality assurance and improvement processes across the sector. Although there is currently no funding it is supported by both Advocacy Tasmania and ATDC and described as being at a 'formative stage'. It is currently focusing on building consumer capacity and skills.*

Most recently Shelter, the peak body for housing and housing related issues in Tasmania, has been exploring the development and possible hosting of a consumer engagement model for people who are homeless. This has involved exploring a model currently being operated by Council for Homeless Persons in Victoria, the Victorian Peer Support and Education Program.

Both DPOs and consumer organisations in other sectors outlined a number of key messages for strengthening disability voice in Tasmania. These are listed on page 28.