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| Department of Communities Tasmaniahousing, disability and community services – disability and community services | Tasmanian Government Logo Picture of Tasmanian Tiger walking through the bush   |
| Tasmanian Community Inclusion and Capacity Development (CICD) – Consumer Voice Public Report |
| Version:  |
| Information accurate as at October 2019 |

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Any queries regarding the project detailed below, should be directed to Disability Services Policy and Programs on (03) 6166 3562 or dspp@communities.tas.gov.au

# Background

In 2016, Tasmania didn’t have a consumer peak organisation for people with disability, and people with disability, advocacy organisations, service providers and government identified the absence of a strong disability voice in Tasmania as a significant gap.

In May 2016, Anglicare Social Action and Research Centre (SARC) released a paper titled *Strengthening the Disability Voice in Tasmania*. This paper highlighted the consumer voice gaps and proposed that an effective strategy, benchmarked from use in other jurisdictions, was the development of a Disability Person Organisation (DPO).

With the implementation of the National Disability Insurance Scheme (NDIS), and major changes in the provision of disability services, it was acknowledged that it was vital that people with disability were represented in policy development, service design and evaluation, quality improvement and future planning.

The National Disability Insurance Agency (NDIA) made Community Inclusion Capacity Development (CICD) grants available in 2016 – 17, 2017 – 18 and 2018 – 19. The objective of the CICD program was to support projects aligned to the Information, Linkages and Capacity Building (ILC) Policy and ILC Commissioning Framework to build readiness of organisations and the community to operate within a nationally consistent approach to ILC under the NDIS.

A grant application was submitted in February 2016 by the Department of Health and Human Services (as the Department of Communities Tasmania was at that time) for CICD funding for a Disabled Person Organistion (DPO) Consumer Voice Mechanism. The proposal of this project was supported by a consortium of interested stakeholders including people with disability, Tasmanian Council of Social Services (TasCOSS) and Disability Support Organisations (DSOs). The Consumer Voice DPO proposal contributed to the CICD program goals and outcome areas of the ILC Framework, but was particularly relevant to the CICD focus area - ‘Delivery by people with disability, for people with disability.’

As stage one of this project progressed, it became apparent that the establishment of a DPO wasn’t appropriate given time, budget and sector capacity restraints, and that a different consumer voice mechanism was required. Consumer Voice Mechanism became the term used throughout the project.

The project was delivered in two stages:

* Stage One: Consultation phase: to undertake the consultation and delivery of a report outlining recommendations which will inform stage two of the project. This stage was undertaken by JFA Purple Orange
* Stage Two: Seeding phase: This phase focused on establishing a consumer voice Disabled Person Organisation (DPO) and placing it on a solid foundation. This stage was undertaken by Disability Voices Tasmania, contracted through Epilepsy Tasmania

# Stage One – Consultation

JFA Purple Orange were the successful applicant to the request for proposal for Stage One of this project, investigating local stakeholder and consumer perspectives on the potential establishment of a collective voice for all Tasmanians living with disability. The consultation also sought to determine how best a collective voice could be established for the current disability community in Tasmania.

109 stakeholders, individuals and family members participated in this project across a range of consultation channels, including agency workshops, public forums, an online survey and a telephone interview.

Participants’ primary concerns with the establishment of a collective disability voice in Tasmania included:

* Ensuring it collectively represented all types of disabilities
* What the impact of a collective voice on the work and members of existing local disability support and advocacy organisations would be
* How it would interact with existing organisations
* The potential duplication of efforts and mechanisms already in place in Tasmania
* Sustainability of the mechanism

JFA Purple Orange also used a co-design method where key stakeholder groups across the Tasmanian disability community were invited to join as members of a co-design group. There is a clear distinction between co-design and consultation, and both methods were used in this project:

* Consultation: beneficiary stakeholder views were sought, with the understanding that the consultation would inform decision making within the project
* Co-design: co-design members views not only contributed to the thinking, but the group also participated in the decisions of the project

The co-design group in this project included representatives from Speak Out Association of Tasmania, Association for Children with Disability Tasmania, Advocacy Tasmania, Brain Injury Association of Tasmania, Autism Tasmania, Tas Deaf, Carers Tasmania, VisAbility/Guide Dogs Tasmania, ParaQuad Tasmania, and a representative from the Minister’s Disability Advisory Council. The co-design group was not expected to be representative of a full range of disability demography, but to be sufficient to help strengthen the likelihood the emerging solution would be helpful to the collective voice of the Tasmanian disability community.

Participants in the consultation and co-design group provided suggestions for how a Tasmanian collective disability voice could be established, which led to the development of five model options for a consumer voice mechanism in Tasmania:

1. A less formal facilitated grass roots conversation
2. A more formal facilitated grass roots conversation
3. More formal, facilitated grass roots conversation, with an explicit early focus on leadership development
4. Establishment of a new DPO
5. Link with interstate and/or international DPOs

Following further needs analysis, JFA Purple Orange recommended the establishment of a formal, facilitated grass roots conversation, with an explicit early focus on leadership.

The Minister for Disability and Community Development endorsed the recommended model.

# Stage Two – Seeding Phase

In April 2018, the members of the co-design group formed as part of the consultation were invited by Communities Tasmania to provide a proposal to inform how the second phase of the project would progress in preparation for ILC commissioning.

The group renamed the project Disability Voices Tasmania and submitted a proposal for stage two of the project, including advising that they would be auspiced through Epilepsy Tasmania. Epilepsy Tasmania was chosen as the auspice organisation as there was no intention for Epilepsy Tasmania to commission for ILC, so it didn’t represent a conflict of interest.

Disability Voices Tasmania was contracted for the following activities:

* Develop a capacity building framework to increase the capacity of people with disability to engage in leadership and consultation activities
* Pilot the capacity building framework with a diverse range of communication and learning styles to reach people state-wide beyond those who are currently active in membership-based organisations
* Develop and pilot a Consumer Voice mechanism for Tasmania that:
	+ Builds connections and relationships based on shared understandings and lived experiences
	+ Provides a channel for information
	+ Builds knowledge capital
	+ Creates opportunities to grow ideas, innovate and co-design
	+ Builds the capacity of individuals to be active and discerning consumers of specialist and mainstream services
	+ Includes considerations for the mechanism’s future sustainability

The original co-design group became the Disability Voices Reference Group, which acted as the supervisory group for this project.

The project was contracted by Communities Tasmania to continue until 31 August 2019, however, the final report was provided in September 2019.

Disability Voices Tasmania advised the following in their final report:

## Consultation

* Further consultation was undertaken to:
	+ Seek organisations’ interests and perspective
	+ Connect with people with disability
	+ Establish credibility and engage support
* People with disability were positive about the pilot, and the opportunity to have an across-disability collective voice. The multi-disability aspect wasn’t viewed as a problem; people saw it as an opportunity to expand inclusion.
* Consultation strategies included a survey, ongoing community engagement, testing a range of collective mechanisms, building capacity through skills-based workshops across the state, and collaboration and representation on working groups and networks.
* People with disability identified stigma and its resulting behaviours and attitudes towards themselves and others as the biggest issue, followed by employment. Stigma is both an experience and a barrier to full participation in, and contribution to, the community.
* 166 people with disability responded to the survey
* The survey highlighted that the majority of people with disability don’t feel heard. However, people engaged with organisations such as self-advocacy groups did express a strong sense of being heard and listened through being able to engage with politicians, and other decision makers.
* A number of people talked about how they have contributed to a consultation, or a survey and never heard the results. This is particularly difficult when the information being shared is often personally important.
* Quotes from the survey included:
	+ ‘There is a tendency in many political and social policy quarters to celebrate the ability while silencing the DIS part of disability; DISadvantage, DIScrimination, DISengagement. Systematic barriers to equal citizenship. Attitudinal barriers. Rights have to be achieved by complaints rather than mandated change.’
	+ ‘A collective voice in Tasmania that could include accessibility would be fantastic at a state level.’
	+ ‘I didn’t realise there wasn’t a collective voice’
	+ ‘It will be great to work collaboratively we can connect young people with disabilities to DVT and you can connect young people with disabilities to us’ – Youth Network of Tasmania
* The results of the survey informed Disability Voices Tasmania’s planning for training, testing mechanisms for collective voices and identifying people with disability wanting to take on a future role with the project.

## Capacity Building Activities

* Disability Voices Tasmania partnered with three organisations with an understanding of human rights and experience in capacity building, to roll out a range of capacity building activities across Tasmania from late June to early September.
* Workshops included:
	+ Working with others
	+ Representing Voices
	+ Developing influence and advocacy skills
	+ Using your story to influence decision makers
	+ Developing your pitch
	+ Working on improving access in the built environment.
* 94 people with disability attended one or more sessions of training. Workshops were held in Smithton, Devonport, Launceston, Hobart, Moonah and Glenorchy:
	+ Smithton: 11 people said they felt they had a better understanding of how government works, how to approach government and how to develop a strategy – and said they felt more confident
	+ Devonport: 1 person wants to become an advocate, and has since enrolled in Cert III community Services, 5 people felt confident they could join and work on an access committee, 1 person wants to work in the area of Disability Voices Tasmania, and 1 person wants to be more active in the community
	+ Hobart: 1 person wants to be a volunteer advocate and 1 person has a mentor and is following up an issue in his community
* Quotes from the workshop, included:
	+ ‘The best part was having a whole bunch of people with disabilities in the same room working and learning together. I have never been in a room where half the participants were in a wheelchair along with me. I have found my tribe.’ Devonport Building Access to Public Buildings and Public Spaces
	+ ‘Best part was group discussion. Learning about people experiences and struggles’ Devonport Building Access to Public Buildings and Public Spaces
	+ ‘To be honest I had reservations as to what I would learn today, but I found this session very helpful firstly with the explicit information and how to use the hierarchy of people to contact (staffers, pollies). I found it extremely useful to learn about questions in parliament.’ Launceston Using your story in influence decision makers
	+ ‘I got a lot out of today I love listening to intelligent people it’s really made me think of things I’d never really considered.’
	+ ‘Developing Influence and Advocacy Skills course is essential if you want to be an effective advocate’
	+ ‘Learning that you need to build a layered approach – preparation and research, identify stakeholders and practice the pitch.’
	+ ‘That there are different places and organisations that can be approached if you find an (access) problem’
* The feedback was positive with people asking if further sessions will be held and recognising that the commonalities of experiences is critical to breaking isolation and beginning to build recognition of commonality and solidarity.
* In response to the question ‘do you now feel more confident to take up leadership/consultative roles?’ one person said, ‘confident not so sure, competent definitely.’ Confidence comes with practice

## Testing the Mechanism

* An observation of the project was how quickly people with disability engaged with the idea of a consumer voice mechanism and began to imagine what it would do and how they would be part of it.
* Disclosing disability in education, employment and the community was raised as an issue for people with disability early in the project and was reaffirmed by responses in the survey and community engagement. To address this, Disability Voices Tasmania worked with the Equal Opportunity Commissioner, UTAS student support, Flourish and the National Disability Coordination Office to explore what the issues were and the best place to begin addressing them. The Brain Injury Association of Tasmania was also interested in this issue, and were successful in obtaining an ILC Grant to take the lead on a project with Disability Voices Tasmania in support.
* Elections and voting was also raised as an issue through this project, and Disability Voices Tasmania undertook a short-term initiative to encourage and support people with disability to register to vote, and then vote. It then came to the attention of Disability Voices Tasmania that there were examples of the votes of people with disability being misused, and Disability Voices Tasmania had a conversation with the AEC to explore the possibility of a longer-term project on this issue.
* Disability Voices Tasmania has been invited to contribute to, and work in partnership with, different initiatives and working groups (such as the Hobart Airport Access Working Group) throughout the project. These invitations indicate a need for skilled people with disability, connected to an organisation to represent issues and work collaboratively in the community.

# Conclusion and Next Steps

* During the project, JFA Purple Orange and Disability Voices Tasmania began to establish and build credibility in the disability and broader community
* In particular, Disability Voices Tasmania reports having established strategic relationships and partnerships with disability organisations and other community and mainstream organisations.
* Organisations with a mainstream focus have sought out Disability Voices Tasmania to add value to projects and recognised the social and economic value in working with people with disability in a co-design approach.
* This short pilot has connected with people with disability, most whom have not been connected to disability services or community organisations and have not had access to capacity building training.
* In July, the Disability Voices Tasmania Reference Group held a planning day to determine the next steps to begin to build a collective voice mechanism.
* Through this process the Reference Group agreed to incorporation as the most logical and effective next step following the JFA Purple Orange Report and the evidence and impact of the work undertaken by Disability Voice Tasmania through this project. The Reference Group subsequently disbanded.
* As per the original intention of the funding for this project, and the opportunities available through the NDIS, Disability Voices Tasmania have been encouraged to seek ongoing funding through ILC commissioning.
* Formation of an interim steering committee, most representatives of whom will be people with disability, is underway as at September 2019. This group’s main role will be to complete the process of incorporation and develop the model for membership, principles of operation and governance of Disability Voices Tasmania into the future.