asid 2025 Conference
Learning from the Past, Shaping the Future

ASID 2025 Conference: *Learning from the Past, Shaping the Future*

Key takeaways and recommendation

- You cannot learn from history if it has been sanitized. Neither can you use it to shape the future.
- No one needs advocacy more than those who cannot self-advocate. One size does not fit all.
- Advocacy must be representative of ALL people with a disability – not become stereotype and social image of those with mild to moderate intellectual disability.

A funded family advocacy peak body would balance the conversation and ensure people with moderate to profound intellectual disability have a voice in the reform conversations that impact them.

Are people with significant intellectual disability adequately represented in matters that affect them?

- History would say no because despite

'nothing about us, without us',

those who have trouble speaking up and advocating for themselves, are left out of the conversations.

- Traditionally families/carers have not had a seat at the table because '*families*' are not disabled!
- While the movement for disability rights has made great progress, this group is often left out of the discussion.

OUR VOICE AUSTRALIA

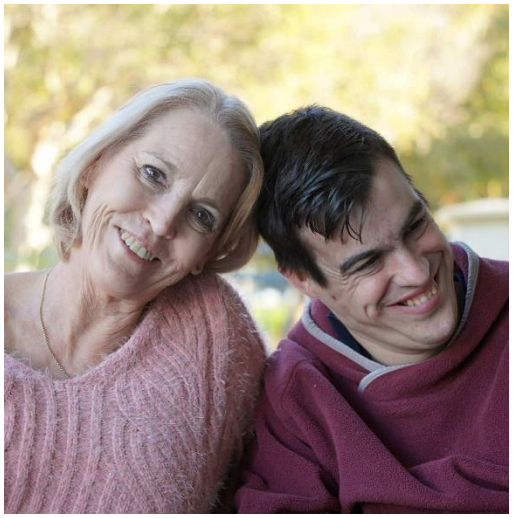
- A national advocacy group that understands, sees and hears the unique needs of you and your family.
- Like you, we value the 'lived experience' of all family members, and we believe government and non-government agencies should too.
- That's why we work with you and for you to 'have your say' in services, legislation, policies and practices that impact you and your family.
- **Our aim is to make sure everyone's voice is heard – not just those who can speak up for themselves.**

Your Voice Our Voice

Australia's voice for people with an intellectual disability and their families.

It has been a frustrating 30+ years…

- People with ID and complex needs who had trouble advocating for themselves, were (and often still are) left out of the conversations that directly affected them. **THIS IS NOT OKAY.**
- We have fought hard to have family carers listened to as they struggled to give their loves ones a voice.
- Things are better but not perfect – it is much easier to dismiss/ignore those who have trouble taking their seat at the table.



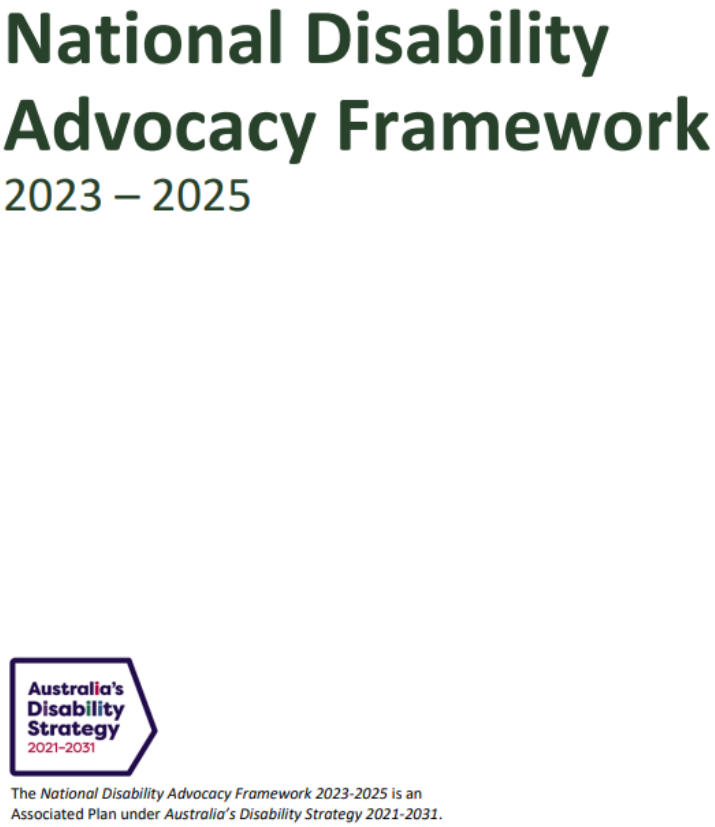
Our two biggest challenges:

- **to have family carers recognised as advocates to speak with their loved ones, and**
- **fairness for all in supported employment.**

Australia's Disability Strategy

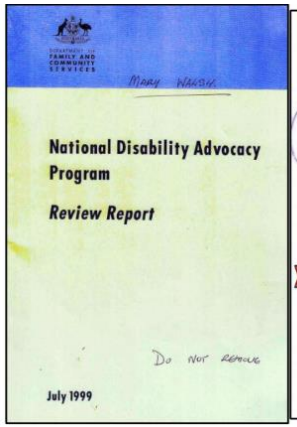
Of responses from people with disability to the public consultation for the National Australian Disability Strategy 2021-2031, people with intellectual disability had the lowest representation (4.5%). 65% of respondents in the same group had a physical or sensory disability.

Learning from history



- From the late 80s, family advocacy has been considered ineligible for funding.
- Dissatisfied with advocacy delivered based on ideological, the Government called a review in the late 90s.
- **The formal report released in July 1999 recommended a mechanism for family representation be in place within a year.**

Historical recognition of family voice



The circumstances of each person with a disability need to be considered individually. It is acknowledged that families exist in a diverse range of households and relationships and that not everyone has a family.

The discussion on the role of families was broadened by some respondents into consideration of ways advocacy organisations operate in general. While some funded services advised that they worked with a client regardless of the issue, others worked in accordance with a set of principles which might result in a client with a different perspective being turned away. One organisation expressed it in the following way: "Each advocacy organisation must choose who it is going to advocate for and with, and really have sincere and genuine reference to those people".

The conclusion reached by the Steering Committee is that, in the past, organisations which have been funded to provide advocacy have carried out their role in accordance with their own operating philosophies. They have not necessarily seen themselves as working within a framework of Government funded services which together contribute to supporting people with disabilities and their families. The Steering Committee recognised that people with disabilities are the primary focus of the program, however, it was noted by the Committee that despite the Government's emphasis on the important role of families, there was no significant representation of the views of families of members with disabilities at the national level.

Remaining Recommendations and Timing of Implementation

I have accepted the remaining recommendations without change. I am concerned, however, to ensure that work on the reform of the advocacy program in line with the recommendations of the report and my decisions on them generally should proceed swiftly.

In particular, I have decided that the recommendations in relation to data and performance measurement (Recommendations 4 and 5), and the recommendation in relation to a mechanism to represent the interests of families with people with disabilities (Recommendation 14) are to be implemented by no later than 1 July 2000.

The final report is to be distributed widely within the disability community, and will be made available as soon as possible in accessible formats, including braille, audio tape and disk, large print and a Plain English version.

I commend the report to all who are involved or have an interest in the delivery of advocacy assistance for people with disabilities.

WARREN TRUSS MP

Parliament House
Canberra

July 1999

Interim Report to the Minister

National Family Carers Voice

representing unpaid family carers of people who were born with or acquired a disability prior to the age of sixty-five.

Introduction

The National Family Carers Voice (NFCV) is a representative group of unpaid family carers. The Government directed NFCV seek input from Family Carers to gather information about the nature, location and circumstances of Family Carers. The purpose of the consultation was to identify the extent of their concerns and provide advice for addressing Family Carers longer term needs.

This Interim Report describes the issues identified by Family Carers through the national survey conducted by NFCV during January 2004. Data was also gathered from wide spread anecdotal evidence and from surveys conducted by disability family networks across Australia, national research by Carers Australia, reports and discussion papers developed by the National Disability Advisory Council to ensure that the issues identified are representative of those that Family Carers experience to either a greater or lesser extent. A bibliography has been developed by the NFCV to provide more detailed information about the plight of Family Carers.

Government savings from the family undertaking a caring role have not been formally investigated, but it is estimated to be millions of dollars saved for each individual with impairment over a life time or many years of care provision. Government support, be it legislative, financial, service delivery or simply recognition for Family Carers, has been minimal in the past and Family Carers have been carrying the ever-increasing care burden alone.

This Interim Report describes the issues and discusses the impact that disability and caring for a person with a disability has on the life of the Family Carer and their family. The issues are reported in order of frequency of occurrence, beginning with the most frequently experienced issue. Each issue also identifies

So important to remember!

"It must not be assumed that people with mild intellectual disabilities can represent the views of those with severe intellectual disabilities or additional mental health problems more effectively than reflexive, involved people without disabilities; or that people with other disabilities are effective proxies for the many different types of people described as having an intellectual disability."

Professor Christine Bigby

Debates about dedifferentiation: twenty- first century thinking about people with intellectual disabilities

De-differentiation- one size fits all ?

De-differentiation in practice

Conflicting narratives about supported employment

‘Such little value’: WA families horrified by Activ’s decision to close disability employment workshops

The future is uncertain for South Australia's major disability employment provider. What does it mean for those it supports?

Royal commission split on future of special schools, group homes and workshops for the disabled

FWC acknowledgment of the family voice

Excerpt of transcript AIRC LHMU & Ors - Matters C2004/4617 - /5981-/6012 - 7-10-2004.

representing LHMU

MS BENNETT: We're not opposed to the ICC being adjourned indefinitely although it might be that if some parties do not have representation during the process. For example where the parties for conciliation might be a little bit more limited than the ICC and it might be convenient at a later time to convene the ICC as a form of information giving but that might be something that during the course of the proceedings we'll be ascertain then.

Following the adoption of the BSWAT into the Award (June 2005) - the ICC was to be used as a review mechanism 12 months after implementation.

PN155

THE VICE PRESIDENT: Thank you, Ms Bennett. I must say one of the obvious features of today is the absence of any representation or application to intervene by any parents group. That may be simply a function of oversight or lack of communication.

PN156

Aust Business Industrial & Vic Chamber Commerce & Industry

MR CAPELIN: Your Honour, I may be able to help. Our office has had discussions with Ms Mary Walsh from the Parents' Association. She was intending to write to the Commission to indicate her intention to seek to intervene was not able to be here today. My understanding from what you said, that correspondence obviously hasn't arrived, but that is what she indicated to our office.

PN157

THE VICE PRESIDENT: Well, since I have been trying to get everyone's position on applications for leave to appear and leave to intervene, is there any objection from any of the parties to leave being given to the parents' group that Ms Walsh represents being given leave to intervene in matter number 4617, and matter number 6123 to the extent that it ends up being joined, or at least linked to 4617?

matter no C6123 was Nojin/Faggotter being represented by DEAC/NCID.

PN158

I note for the purposes of the transcript that there is no objection raised by any of the parties present today, or the representatives today.

PN159

Excerpt - Para 110 - page 35 (Association for Employees with a Disability v Commonwealth of Australia [2021]FCAFC 36.

Fifth respondent's submissions

110 Our Voice Australia agreed with and adopted the written submissions of the second, third and fourth respondents, and made some additional submissions based on the experiences of its members with family members employed in the ADE sector. In her oral address to the Court, Ms Walsh emphasised that the Commission's process had once been described by lawyers involved as "argy bargy". She emphasized to the Court that this "argy bargy" was about the lives of those parents, family members and carers who make up ~~One~~ our Voice, and about the "lived examples" of the debate about what wage structure should be implemented for employees with a disability who work in ADEs. Her observations have, with respect, force, and they underline why the Commission, in the circumstances, must be permitted to complete its statutory task.

Supported employees having a say

Our Voice

[61] Our Voice tendered 14 anonymised witness statements[91] (the unredacted versions having been provided only to the Commission) from current supported employees of the ADE operated by Activ Foundation (Activ) in Western Australia. Activ is expected to cease its ADE activities at the end of 2023.[92] We directed that the 14 employees were not to be the subject of cross-examination. Their witness statements were demonstrative of the following broad propositions:

- they are unhappy about the expected impending end to their employment with Activ, and fear that they will not find alternative employment afterwards;
- some of the employees have worked for the same ADE for a long time, with the longest-serving of the 14 having worked for Activ for over 50 years;
- approximately half of them have tried open employment, but all who had done so had negative experiences and returned to work in ADEs; and
- the employees greatly enjoy the dignity, sense of purpose and social interaction that working at an ADE has provided them, and worry that they will become sad, bored and lonely if they cannot work there any longer.

What can family advocacy achieve?

31. Rights at work for supported employees

[32 renumbered as 31 and varied by PR749151 ppc 30Jun23]

31.1 When dealing with employment matters affecting supported employees the employer shall take all reasonable steps to provide such employees with the information they require to exercise their employment rights.

31.2 Such reasonable steps will include, but are not limited to, the following:

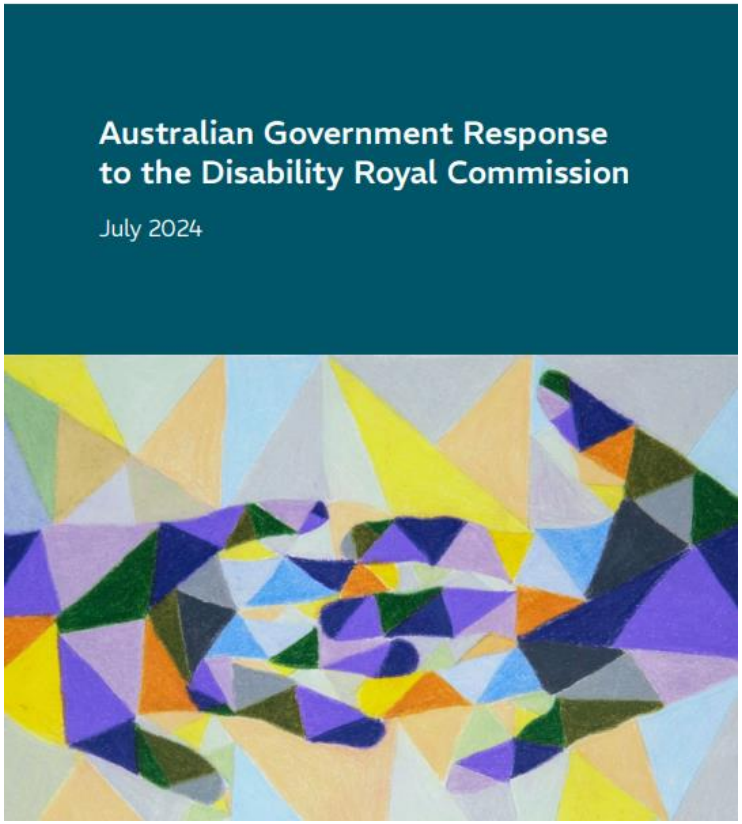
(a) providing information to supported employees of their right to be a member of the union and be represented in the workplace by a union representative;

(b) providing information in relation to seeking information and or assistance from the Fair Work Ombudsman;

(c) providing information to a supported employee about their right to have their nominee, guardian, carer, parent or other family member, advocate or union assist them in making decisions about employment matters.

Disability Royal Commission

Australian Government



Response to Recommendation 7.31

Responsibility: **Australian Government**

Response: **Subject to further consideration**

The Australian Government requires further consultation with a range of stakeholders before committing to broad reform for supported employee wages. The Disability Royal Commission commissioned research and modelling into the impacts and costs of the proposed wage increase, with modelling indicating there could be significant job losses for people with disability being paid supported wages.

Consultation will require a strong focus on the impact of implementation on supported employees, as outlined in the Royal Commission's Final Report.

Response to Recommendation 7.32

Responsibility: **Australian, state and territory governments**

Joint Response: **Subject to further consideration**

The Australian Government will undertake consultation to further consider views and implications associated with this recommendation and then determine next steps. Disability Ministers will also update the Supported Employment Plan in 2024.

Disability Royal Commission quote

"We have now read your submission regarding the importance of maintaining Australian Disability Enterprises as an option for the employment of people with disability. ***We hear your assertion that dismantling Australia's current supported employment model would override the career aspirations and desires of many workers."***

- — Disability Royal Commission

Square pegs into round holes

The now – and - the future

Activ (WA): Jobs – on the line

Workers and their families were consulted by OVA and given a voice!

OFFICIAL

Meet some of the people who fought for their right to work when activ announced their closure in 2022.

They were listened to and now proudly work for WorkPower who took over the Activ sites. Without family intervention, those 770 jobs would have been lost completely and their voices would never have been heard.

The right to be heard is a basic human right.

QUESTIONS and food for thought ?

- Are pay rates for supported workers fair?
- Why can’t everyone move in to open employment with support?
- Aren’t supported workplaces segregation?
- Are jobs in supported employment meaningful?
- ?????

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Add your voice to ours…