



**Government of  
South Australia**

# **Future Safeguarding for People with Disabilities**

## **Discussion Paper**

**September 2021**

**Interim Report to Minister for Human Services**

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## 1. The Issue

The most common concern of parents of a son or daughter with a disability is “what will happen to my son or daughter when I am no longer able to look out for them?” Usually, parents and other family members are preoccupied with matters rooted in the here-and-now – “how do I get enough therapy?”, “where is my respite coming from?”, “who do I contact in the NDIA<sup>1</sup> when things go belly-up?”.

Behind the pressing problems of the present, usually not far below the surface, is an existential angst about the welfare of their son or daughter after they are no longer able to care for them. Often parents do not want to burden their other sons or daughters with sibling responsibility after they have died or become too frail, but they are racked with anxiety about who will care.

The tragedy of Ann Marie Smith in 2020 was a clarion call for addressing this issue. Ann Marie’s parents made excellent financial provision for her and yet, after they died, their worst nightmare happened. Ann Marie died in horrific circumstances, allegedly, because of criminal neglect. No-one watched out for her and made sure she was OK. Ann Marie’s parents had left her financially well supported. She had a home to live in, a car to cover her transport requirements and money for her everyday needs. However, this proved to be insufficient to safeguard her from a sole support worker who neglected basic care for her, and a service provider who failed to oversee the support worker’s daily practice.

Question 1: How can parents make provision for their son or daughter with a disability so that they will be well cared for after the parents are no longer around?

## 2. Safeguarding Task Force

The Minister for Human Services established the Safeguarding Task Force on 21 May 2020 in response to the death of Ann Marie Smith. People with disabilities, parents and carers alike were horrified by what occurred in the last 12 months of Ann Marie’s life and the manner of her death. Tasked with the responsibility of examining and reporting on safeguarding gaps, the Task Force looked at areas that needed strengthening in safeguarding arrangements for people with disabilities living in South Australia.

The membership of the Task Force comprised people with a lived experience of disability, family members, service providers and state Government officials. The co-chairs of the Task Force (disability rights advocate Kelly Vincent and disability advocate David Caudrey) also met with a wide variety of people who spoke about safeguarding issues. The Safeguarding Task Force Report that was provided to the Minister identified a total of 14 gaps, and from these gaps 7 recommendations were

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<sup>1</sup> NDIA – National Disability Insurance Agency

made. The South Australian government accepted all 7 recommendations and have acted on them. A copy of the Report is available on the OPA website at [opa.gov.au](http://opa.gov.au).

During the process of information gathering for the Report it became clear that there was a heightened level of anxiety from parents around what happened to Ann Marie Smith and what could be done to ensure that did not happen to their son or daughter when they are no longer around.

*“Will my beloved son or daughter be looked after properly when I am gone or can’t care for them anymore?”*

*(The Safeguarding Task Force Report, September 2020)*

The safeguarding gaps identified in the Report did not fully address the fundamental problem of ensuring that there would be an independent caring person (or caring people) looking out for Ann Marie and making sure that she was OK.

Question 2: Who can be relied upon to care that a person with a disability is OK if parents are too frail or have passed away?

### 3. Purpose of this study

In July 2021 the Minister for Human Services requested that the Disability Advocate consider further safeguarding measures and examine the issue of future planning for people with disabilities when parents and caregivers are no longer able to provide care.

The best safeguard for any person with a disability is that there are measures to increase the social connection of the person, so that there are more independent and concerned people in their lives. At the same time, the person with a disability needs to be able to take as much control of their life as possible. When a person has control and there are other caring people around, they are safer, and that usually leads to a better quality of life.

Terms of Reference for this study were developed (see Attachment 1) to clarify the focus of the work and as an information sheet to provide to families, advocates, and service providers about the work being undertaken.

#### Terms of Reference

This study will:

1. Explore how parents can best make provision so that, when they are no longer able to offer support, their son or daughter with a disability will continue to have someone to look out for them and ensure that they are OK.

2. Explore forms of trust arrangement which could be offered by a non-government organisation or by trusted individuals.
3. Consult with, and involve, a wide range of individuals and stakeholders, including but not limited to, people with disability, parents, carers, supporters and advocates, to ensure a co-design approach is undertaken when considering recommendations.
4. Consider safeguards against exploitation of a vulnerable person with a disability to promote respect and choice for supported decision-making and individual autonomy.
5. Produce a discussion paper for the Minister by 30 September 2021, based on analysis of past research and initiatives, and using advice from individuals with knowledge in this area.
6. Circulate the discussion paper and consult the wider community.
7. Prepare a final report for the Minister by 15 December 2021.

The method used to gather information comprises individual interviews with families, advocates, and service providers. Several interviews occurred leading up to the completion of this discussion paper. Interviews took up to an hour each. Common themes were extracted, and possible actions have been noted.

Research was also undertaken to provide a national and international context to practices in South Australia, in support of safeguarding and future planning.

## 4. Previous Initiatives

### 4.1 Mitchell Inquiry

In 1985, Dame Roma Mitchell released the *Review of Services for Behaviourally Disordered Persons*. The Review covered many topics that recommended improvements for South Australians with severe personality and behaviour disorders. The Review made a host of recommendations including improved data collection, the development of a Behaviourally Disordered Persons Management Committee, the development of community accommodation services and legislative changes.

The Review also acknowledged that consideration should be given to information and training programs for families and caregivers. The review suggested the training was to include the nature of the disorder and adjustments required over time. It is also acknowledged that families could benefit from counselling through life stages and that people may need these supports for long periods of time.

It was recommended that:

- Expert help is required for agencies, caregivers and families and must be readily available to provide intervention and support to families and caregivers who are trying to cope at home.
- A resource list should be made available with support and intervention as necessary. Special support services should be always available.

- A venue should be provided for people to meet and support each other and contribute to the mental health of caregivers.

This report acknowledged the key role of families in support and planning.

The Mitchell Review led to the establishment of the Management Assessment Panel which has now become a part of the Exceptional Needs Unit in the Department of Human Services (DHS). The Review was an early example of considering the central role families play in the lives of people with disabilities.

#### 4.2 Guaranteed Care

In October 1994 Bev Freeling (Parent) and Richard Bruggemann (Chief Executive Officer of the Intellectual Disability Services Council) presented a paper on Guaranteed Care to the National ASID/NCID Conference in Perth. The paper commenced discussions on the topic of what the future holds for a person with a disability when their parent dies, or due to advanced age or incapacity can no longer provide the direct care or coordination of support the person with a disability requires. From these discussions grew the concept of *guaranteed care*.

*Guaranteed care* had two components, the first being the development of a detailed plan that would incorporate:

- future accommodation and support needs for the individual when the parent is no longer there or able to provide care,
- guardianship and advocacy,
- financial administration,
- vocational activities,
- recreational, cultural, and sporting pursuits,
- ongoing health monitoring and provision of medical services, and
- matters specific to an individual (e.g., in some cases ongoing use of the family home or financial provision).

The second component concerned the guarantee that prior planning by parents for the care of their son or daughter on their death or incapacity will be executed according to their wishes. This is where the concept of future planning comes into play.

*"There can't be just one person in this world looking after a person with a disability"*

*(The Safeguarding Task Force Report, September 2020)*

The role of parents in the coordination of supports that a person with a disability requires has been hugely exacerbated by the arrival of the NDIS. The NDIS does not fund comprehensive case management but relies on a cast of players, none of whom has the default role of "pulling it all together". That role usually now falls to families. It is families that make sure the service provider is up to scratch in their dealings with their son or daughter. Who will do that when you are no longer there to police the quality of care?

### 4.3 Circles of Support and Micro-Boards

Circles of support were introduced in Canada around 15 years ago. Since then, Circles of Support & Accountability (COSA), has been successful in Canada in assisting people with disability to have a voice and achieve life goals.

Projects based on this model are now in place in the United Kingdom, United States, New Zealand and Australia. Circles of support are a method of bringing people together, creating a structured network of friends and relatives who give their support to a person with a disability and work together to build the individual's capacity to live an inclusive life. Circles of support are effective in increasing community involvement and achieving life goals while reducing reliance on paid services. They can also be a useful safeguard for the future as each member of the circle forms a relationship with other members of the group and with the person with a disability.

*"People keep people safe"*

*(Jayne Barrett, Community Living Project)*

In South Australia the Community Living Project developed and improved the model of circles of support. The establishment of a circle requires planning and coordination. A facilitator works with the person with a disability to intentionally bring together people who are identified as willing and capable of making a positive contribution. The facilitator gets to know each person and the family well and works with them to deliberately invite other people into their life with a view that they might look out for the person in the longer term.

A related concept to that of circles of support is the *micro-board*, also a group of willing people prepared to make decisions supporting a person with a disability. The legal status of micro-boards is being examined by the South Australian Law Reform Institute (SALRI), at the University of Adelaide.

Question 3: What role do circles of support play in future safeguarding of people with disabilities?

### 4.4 Siblings

In the disability sector, siblings may be overlooked as possible long-term care options due to the assumption that siblings will not want to be involved or that the parents do not want to burden siblings with the care of their brother or sister. However, siblings often worry about what will happen to their brother or sister when their parents are no longer around but are not always involved in the planning process.

The role of a sibling in the long-term care plan of a person with a disability will vary depending on the family dynamic. A sibling can support their brother or sister in a formal capacity as a full-time care giver alongside parents or in a more informal way e.g. supporting their sibling by meeting up for lunch, taking them shopping, assisting with social gatherings, and providing social interactions. Where possible a close relationship with a sibling can help a person with a disability experience higher levels of satisfaction.

*"I think it is sad to think about people with a disability whose only relationships are with people who are paid. We must do what we can to nurture relationships with siblings. If supported, these relationships can be the longest of any"*

Question 4: What role can siblings play when parents are no longer around and what supports might they need?

*(Kate Stroh, Siblings Australia)*

#### 4.5 Future Planning

Future planning is a method of creating a plan for a person with a disability that reflects the wishes of the person, their parents, siblings, friends, and extended family. Future planning is important because it can bring the whole family together for dialogue and decision-making, leading to better outcomes by intentionally planning for the future (Heller & Caldwell, 2006).

Having a plan can provide parents and caregivers with peace of mind that their son or daughter has a future that is safe and secure. Future planning can be done at any point but is most often done when a person is transitioning from living in the family home to a new living arrangement due to parental death or incapacity. Early planning can give parents confidence that their son or daughter has strong relationships in place, that have been developed over time, for them to continue to live a safe and productive life both before and after the parents' death or incapacity.

*"The more people a person has who are actively involved in their life, the safer they will be in the long term".*

*(Laynie Dunne Heynis, SACID)*

There are several initiatives both locally and nationally that have been developed, often by service providers, to assist parents with navigating the NDIS, writing a will, future planning, circles of support and memoranda of intent.

- The *South Australian Council on Intellectual Disability (SACID)* offers future planning workshops. These workshops have been co-designed with parents and caregivers and are funded through NDIS Information Linkage and Capacity building (ILC) grant funding. The three-hour workshops cover wills and guardianship, micro-boards, circles of support and supported decision making.
- The *Strong and Capable Cooperative* was started by people with a disability, for people with a disability living in the northern suburbs of Adelaide, to achieve more from the National Disability Insurance Scheme (NDIS) through outcomes such as increased plan utilisation. The cooperative shares knowledge, provides advice and recognises service providers who do the right thing. The cooperative says that "carers are often the forgotten heroes when it comes to the NDIS" and will provide support and information and events for carers.
- The *National Alliance of Capacity Building Organisations (NACBO)* is a national network of not-for-profit, values based, capacity building organisations. (See

Attachment 2). Belonging Matters, Imagine More, Valued Lives, Future Living, Community Resource Unit, and the Future Proofing Project are all members of NACBO and are helping families navigate future planning through education. Their programs are designed to assist families in considering the issues involved when planning future arrangements for the ongoing care of their family member in a way that is positive, flexible, sustainable and fulfils the wishes of the family and the person living with a disability.

- *Future Living* is a registered NDIS service provider in Western Australia that has supported families for 30 years to plan and implement services that provide a secure future. Future Living established a personal support service (PSS) that offers lifelong visiting and advocacy from the time that parents are unable to provide support. A PSS contract is calculated by an actuary based on life expectancy, similar to an insurance policy. This can be paid in installments or as a lump sum. PSS provides a visit every two months with a visitor who is selected by Future Living as a match to the person with disability. At the end of each visit a feedback report is provided to Future Living. Any concerns raised from the visit are discussed with siblings and service providers.

Question 5: Should capacity building grants be available through the NDIS Information Linkages and Capacity Building Program to provide information and training on future planning initiatives?

Question 6: What value do you see in the development of a Personal Support Service in SA?

## 5. Wills and Trusts

The State Government of South Australia founded the Public Trustee in 1881 to administer deceased estates, including the estates of those people dying intestate. Whilst deceased estates administration and trusts have remained core business, the Public Trustee also provides financial and administrative services to eligible South Australians. The Public Trustee makes Wills and Enduring Powers of Attorney for eligible concession holders and for those people who are under administration or protection orders through the South Australian Civil and Administrative Tribunal (SACAT). The Public Trustee is an agency of the Attorney-General's Department and a Government Business Enterprise.

### 5.1 Special Disability Trusts

Since 2006 families have been able to arrange a Special Disability Trust (SDT) for the current and future care and accommodation needs of a person with a severe disability or medical condition. The trust can pay for any care, accommodation, medical costs, and other needs of the beneficiary during their lifetime. To qualify for a Special Disability Trust (*Social Security Act 1991* (Cth)) the primary beneficiary must have a "severe disability" which is assessed by the Department of Social Services Special Disability Trust Team. The term 'Special' refers to the social

security and tax treatment of the trust and is not a reference to the beneficiary's disability. In South Australia, as there is no perpetuity period, trusts can last forever, until such time as the trustee winds the trust up.

Rod Genders' (2020) paper on Special Disability Trusts acknowledges future planning issues as well as the financial aspect of a Special Disability Trust. Genders speaks of the concerns of parents, guardians, and carers of "how the protected-person will be supported in the future when the guardians are no longer able to provide the love, support and care themselves". Genders recommends that time is spent on reflecting on what the families hopes and dreams are for the person's future and what aspirations that the individual holds for themselves. Genders touches on safeguarding by advising that "a secure and sustainable future-will be more likely achieved if they have other people in their lives who are committed to assisting them in the long term".

## 5.2 Memorandum of Intent

Conceived by the Academy of Special Needs Planners in the United States, a *memorandum of intent* is a document, much like a letter, that can be used by parents to communicate their preferences regarding the ongoing care of their son or daughter in the event of death or incapacitation. The memorandum of intent is designed to give trustees insight and information regarding supports, services and personal matters concerning the person with a disability. Included in the memorandum of intent are details of financial support, living arrangements, services being used, programs currently being participated in, the abilities of the person and any personal preferences the person with a disability might have about their care.

While not legally binding a clearly written memorandum of intent provides information for trustees regarding the day to day needs of the person with a disability in a way that enhances their independence and growth and encourages them to pursue their interests. It is recommended the memorandum is filed with a legal will to provide easy access to the content when required.

Parents interviewed also expressed concern that their son or daughter with disability is currently not able to make a legal will unless they have testamentary capacity and have suggested a legislative change is required to alter this.

Natalie Wade of Equality Lawyers suggested that there needs to be law reform that supports future planning. Expanded powers for supported decision making rather than substitute decision making as substitute decision making can work against human rights.

*"You keep people safe by having their human rights protected"*

*(Natalie Wade, Equality Lawyers)*

Question 7: Do you support use of Special Disability Trust or a Memorandum of Intent?

## 6. Common Threads

Thinking about the future can be challenging for families. With the introduction of the NDIS there have been significant changes made in the way services are provided. Whether their child with a disability lives at home or in supported arrangements many parents continue to be the primary source of knowledge, support and advocacy and are required to navigate the NDIS. According to families, while the principles of the NDIS are good it takes a lot of effort to access the systems and services.

*“The difficulties for families are made worse due to the complex and combative nature of the NDIS. Even young parents are wondering how they will be able to keep doing this in the future”*

*(Tanya Day, DACSSA)*

*“We hear from and assist parents in their 80’s who are still trying to understand and navigate the complex systems of services”*

*(Kendall Field, DACSSA)*

### 6.1 Case Management

The issue of case management and support coordination was well-documented in the Safeguarding Task Force Report and was again highlighted as a concern in this series of interviews. It is believed that there is a need for more assertive case management to enable people with disabilities and their families to navigate complex service systems, especially where families have lower levels of literacy or are from CALD backgrounds.

### 6.2 Community Visitor Scheme

During the meetings with families, advocates and service providers several people raised concerns about the changed role of the Community Visitor Scheme (CVS). This was acknowledged during the Safeguarding Task Force and led to Safeguarding Gap 12 viz. *The commencement of the NDIS Quality and Safeguards Commission on 1 July 2018 in South Australia has created issues with the scope of the Community Visitor Scheme.*

The scope currently includes state government accommodation and clients of the Public Advocate who are NDIS participants only. The role of the CVS is valuable, and many people have expressed the view that it should include visiting services in the non-government sector. It was recommended in the Safeguarding Task Force Report that the NDIS Quality and Safeguards Commission should run or auspice a national community visitor scheme.

### 6.3 Information, Linkage and Capacity Building grants

The NDIS has not made best use of the Information, Linkage and Capacity Building (ILC) grants program. The ILC grants are meant to target the building of the capacity of society to include people with disabilities and also the capacity of individuals to engage with society and exercise their choices in life and to take control.

There are a number of programs that currently use ILC funding to support people with disabilities and their families to navigate the NDIS or to develop future plans.

Because of the key role ILC grants play in capacity building for individuals a review of the ILC process needs to be undertaken to consider grants that are not time limited and the wider dissemination of grant reports to enable learnings to be available to other service providers.

#### **6.4 Individual Advocacy**

Funding by the State for individual disability advocacy ceased in 2007. However, as a result of the Safeguarding Task Force Report the State Government provided an additional \$1.8 million over 3 years to continue the work of the Disability Advocate and to support individual advocacy. It is still evident that access to advocacy agencies is difficult and remains a concern.

Question 8: What value do you see in individual advocacy services?

### **7. Questions**

Question 1: How can parents make provision for their son or daughter with a disability so that they will be well cared for after the parents are no longer around?

Question 2: Who can be relied upon to care that a person with a disability is OK if parents are too frail or have passed away?

Question 3: What role do circles of support play in future safeguarding of people with disabilities?

Question 4: What role can siblings play when parents are no longer around and what supports might they need?

Question 5: Should capacity building grants be available through the NDIS Information Linkages and Capacity Building Program to provide information and training on future planning initiatives?

Question 6: What value do you see in the development of a Personal Support Service in SA?

Question 7: Do you support use of Special Disability Trust or a Memorandum of Intent?

Question 8: What value do you see in individual advocacy services?

### **8. Conclusion**

The best safeguard is for any potentially vulnerable individual with a disability is to have a number of people in their lives who will make sure that they are not left to their own devices when things go wrong. An extra pair of eyes can notice if a person's situation has changed or if something doesn't look right and can act accordingly. This is where siblings can play an important role.

*“Ann Marie Smith’s family surely thought they had done everything right”*

*(Sam Paior, Parent / Director, The Growing Space)*

Thinking about the future while navigating the present can be extremely daunting for parents and carers. Facing their own mortality, legal and financial issues, and lack of information are all barriers to planning for the future.

Creating a plan early could assist parents in feeling more comfortable that, in the event of their death or incapacity, their son or daughter has the necessary supports already in place for them to continue to live a safe and productive life.

Future planning is not limited to addressing financial means but also details the social and practical supports that the person with a disability requires. While organisations exist in the state, many families are not aware of the organisations or the assistance they provide.

Our focus needs to be on families being better informed about the services these organisations provide so they know there is somewhere they can go for help when planning the future wellbeing of a person with high support needs. Existing services do not cover the field and we need to stimulate interest in future planning among a wide range of agencies, so that parents can have choice of an agency that they trust to still be around in future years and to still be providing an accountable quality service to their son or daughter.

## **9. Next Steps**

This discussion paper has identified a number of possible initiatives that would address the safeguarding question, regarding the ways in which other caring people can be in the life of a person with a disability after their parents have passed away or become too old and frail to undertake the safeguarding tasks.

The issue for parents is: “who do you trust to still be around 5 or 10 years after you die who will sustain a caring interest”.

The people we spoke to were well aware that the best ongoing safeguard is the presence of other family members who care and will actively look out for the person with a disability. However, many people with disabilities do not have this family support network. Siblings can live far away or have their own families to look after.

The next phase of the study is to continue to interview families and to seek feedback on the questions posed in this discussion paper. The Disability Advocate will continue to meet with individuals, families, advocates and service providers to further canvas and explore common threads and clarify where to go from here.

A report with recommendation will be prepared for the Minister for Human Services on December 15, 2021.

## 10. Attachments

### Attachment 1:



Measures to safeguard people with disabilities through Family Trust arrangements

#### Study by Disability Advocate, David Caudrey

##### Terms of Reference

##### **Background**

In 2013, the National Disability Insurance Scheme (NDIS) commenced operation in South Australia. After 3 years of trial and 3 years of transition, the NDIS is now fully operational. South Australia has 39,600 active participants in the NDIS (March 2021).

The State has specific prescribed roles under the NDIS Agreement with the Commonwealth viz. conducting worker screenings and authorising the use of restrictive practices. Otherwise, the Commonwealth is responsible for all matters regarding the support services for people with disabilities, including registering service providers and maintaining standards.

Service quality and participant safety are matters for the independent NDIS Quality and Safeguards Commission (the Commission).

The Safeguarding Task Force Report (2020), following the death of Ann Marie Smith, identified 14 gaps, and made seven recommendations (see Attachment for a list of the 14 gaps and their status).

Key recommendations of the Task Force that have involved additional State funding are:

- expansion of the role of the Adult Safeguarding Unit to include NDIS participants under 65 years, and
- funding of individual advocacy for the first time since 2008.

Other recommendations of the Task Force include: -

- better client information exchange between Commonwealth and State agencies,
- endorsing the value of a Community Visitor Scheme, and
- ensuring that support for regular medical checks is included in participants' plans.

While the Safeguarding Task Force (2020) addressed the safety of vulnerable NDIS participants in SA, the *Royal Commission into Violence Abuse, Neglect and Exploitation of people with Disability* is examining the national question of

safeguarding and all its ramifications but is not due to deliver its final report until late 2023.

### ***Safeguarding through Family Trust arrangements***

The best safeguard for any person with a disability is that there are measures to increase the social connection of the person, so that there are more independent and concerned people into their lives. At the same time the person with a disability needs to be able to take as much control of their life as possible. When a person has control and there are other caring people around, they are safer, and that usually leads to a better quality of life.

The most common concern of parents of a son or daughter with a disability is “what will happen to my son or daughter when I am no longer able to look out for them?” Usually, parents and other family members are concerned with matters rooted in the here-and-now – “how do I get enough therapy?”, “where is my respite coming from?”, “who do I contact in the NDIA when things go belly-up?”. Behind the pressing problems of the present, usually not far below the surface, is an existential angst about the welfare of their son or daughter after they are no longer able to care for them. Often parents do not want to burden their other sons or daughters with sibling responsibility after they have died or become too frail, but they are racked with anxiety about who will care.

The case of Ann Marie Smith is a clarion call for addressing this issue. Her parents made financial provision for her – a nice home, a car, enough money to manage a good middle-class life and yet their worst nightmare happened. Ann Marie died, allegedly, because of criminal neglect. No-one watched out for her and made sure she was OK.

### **Terms of Reference**

This study will:

1. Explore how parents can best make provision so that, when they are no longer able to offer support, their son or daughter with a disability will continue to have someone to look out for them and ensure that they are OK.
2. Explore forms of trust arrangement which could be offered by a non-government organisation or by trusted individuals.
3. Consult with, and involve, a wide range of individuals and stakeholders, including but not limited to, people with disability, parents, carers, supporters and advocates, to ensure a co-design approach is undertaken when considering recommendations.
4. Consider safeguards against exploitation of a vulnerable person with a disability to promote respect and choice for supported decision-making and individual autonomy.

5. Produce a discussion paper for the Minister by 30 September 2021, based on analysis of past research and initiatives, and using advice from individuals with knowledge in this area.
6. Circulate the discussion paper and consult the wider community.
7. Prepare a final report for the Minister by 15 December 2021.

## Attachment 2:

### National Alliance of Capacity Building Organisations (NACBO)

#### Capacity Building for Inclusive Lives

The National Alliance of Capacity Building Organisations is a national network of not-for-profit, values based, capacity building organisations. We have a shared vision and belief that all people with a disability are valued citizens and have the right to contribute to society through social and economic participation.

We acknowledge that many people with disabilities are shut out from the richness of many ordinary experiences through outdated practices that limit people's lives. To shift this paradigm, members of the alliance provide information, education, mentoring, planning, peer support and leadership development.

Our aims as an alliance are to:

- Build people's knowledge, shift mindsets, and strengthen values-based leadership so that Australians with a disability are empowered to have full, meaningful and inclusive lives that are rich in relationships and
- Support and safeguard not-for-profit organisations in Australia who do this work, and
- Strengthen people's skills and competencies to enable social and economic contributions.

Collectively, the Alliance has an impressive online national presence that contains high-quality materials on global and local best-practice of community inclusion.

In 2017-18 year, NACBO worked with 20,000 people directly and had connected with 250,000 Australians online.

Our network includes the following organisations, who have more than 80 years of combined experience in regard to shifting mindsets:



**Belonging Matters** in Victoria is a not for profit, values driven, education and advisory service developed in 2003 by people with a disability and families concerned about the systemic exclusion of people with a disability.

Our aim is to change attitudes positively by portraying people with a disability as valued citizens with abilities, passions and contributions to make to society. This is done through a range of capacity building methods including personalised mentoring; Circles of Support facilitation, leadership development, peer to peer

support, film production, publications, workshops and six national conferences! These investments have not only shifted thinking but empowered people with a disability to pursue opportunities such as open employment, mainstream education and authentic community involvement.

Belonging Matters has also recently partnered with the University of Melbourne, drawing on the valuable contribution of NACBO, to produce 19 Stories of Social Inclusion.



**Community Resource Unit (CRU)** in Queensland has a mission to engage a broad range of people in a movement for change so that people with disability will be welcomed and appreciated as they take their place in their communities. CRU is based in Brisbane, but works state-wide.

CRU's origins lie in a 1987 initiative of families, professionals and people with disabilities who recognised that legislative change was insufficient to support authentic change. CRU invests in values-based leadership development; engages on questions of values and vision; provides inspiration, analysis and assistance to shape relevant support arrangements. CRU does this through workshops, publications and a small amount of project work with individuals and agencies.

CRU was previously funded by the Queensland Government to deliver the states NDIS Participant Readiness Initiative. Our face to face and on-line strategies assisted people to be clear, informed, confident, ready and connected in the lead up to the NDIS



**The Institute for Family Advocacy & Leadership Development** in New South Wales is a state and federally funded disability, advocacy organisation. Family Advocacy was founded over 25 years ago by a group of concerned families of people with disability who had a clear vision of a fully inclusive life for their family

member. Our goal is to advance and protect the rights of people with developmental disability in achieving authentically inclusive lives and enjoy the same opportunities and living conditions as the majority of Australians.

The organisation has a high presence and profile across the State and its work involves: building the capacity of families to undertake an advocacy and leadership role; a capacity building project, called **Resourcing Inclusive Communities**; making representations to Government regarding inclusive legislation, policy, funding, monitoring and practice, that meets the needs of people with disability living everyday typical lives; and providing advocacy related information, support and advice to families about inclusive education, community, employment, housing. This function supports families to be the strongest advocates they can be for their family member with disability.



**Imagine More in Canberra** is a grassroots, family-led organisation founded in 2013. We believe in a community where everyone is included, valued, and contributing in meaningful roles. We invest in individuals, families, and the community. It's our aim to inspire and motivate others to ensure people with disability

- hold valued social roles
- develop meaningful relationships and
- live typical lives in their communities.

Our most powerful methods to show what is possible are **storytelling** and **working with one person at a time**. Leading by example, we help others to understand how people with disability can

- take up valued social roles
- establish a Circle of Support
- experience an inclusive education
- find meaningful employment
- live in a place they call home.

We do this through

- having kitchen table conversations
- facilitating peer support groups

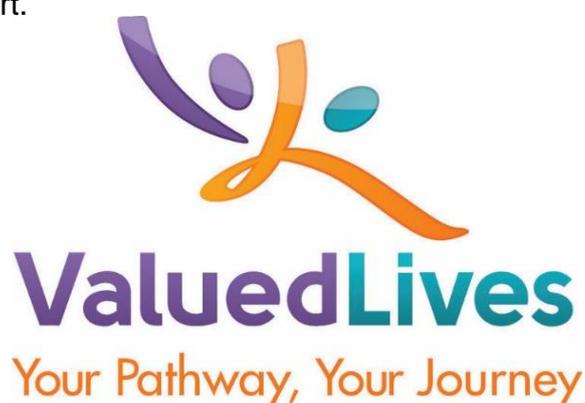
- mentoring others to take action to get the good things of life
- holding topic-based workshops and conferences
- strengthening family leadership.



**JFA Purple Orange** in South Australia was founded in Adelaide in 2006 to advance people's chances of a good life. Our work involves information, social policy, capacity-building, consultancy, evaluation and systemic advocacy. We also host consumer led initiatives. Our primary 'moral' stakeholders are the disability community of South Australia, and then nationally. Our 'legal' stakeholders are our board, typically including at least 50% with lived experience of disability.

Our approach is based on dialogue, to understand the issues that stand in the way of a good life, and to assist people's connection to information and each other. This includes workshops, focus groups, forums, surveys, and peer networks. Much of our work translates to policy submissions and other publications.

Our approach includes Co-design and Co-production, and is anchored on our Model of Citizenship Support.



**Valued Lives Foundation** is a peer-led community support organisation operating as a social enterprise since 2013 in Western Australia. Bronia Holyoak is the Founder and CEO at Valued Lives. Valued Lives mission is to assist people to live Valued Lives in welcoming communities. Over 75% of our board and staff have lived experience directly or have a family member with a disability.

Peer support is the foundation of our work at Valued Lives as we believe that people who have shared experiences can offer invaluable knowledge, experience and support to others who are on a similar pathway. We host peer support networks on

line and in local communities led by family members. We facilitate workshops and training around contemporary person centered approaches and building community and informal networks and promote self-directed supports and services.

Valued Lives Foundation has been involved with several NDIS initiatives, we were a non- government provider of Local Area Coordination in WA; when people transferred to the NDIS we commenced delivering capacity building strategies and support coordination. Valued Lives was the lead agency for the Alliance Project (Perth Hills) aimed at delivering alternative planning options for NDIS participants. The organisation has a strong interest in the development of Microenterprises for people with disabilities and are currently leading an ILC funded project to provide coaching and mentoring for budding entrepreneurs in Western Australia.

## Attachment 3:



### Future Planning or people with disability (with ageing carers)

In 2020 Minister Lensink requested that the Disability Rights Advocate Kelly Vincent and Disability Advocate David Caudrey Co-Chair the Safeguarding Taskforce. During the process of information gathering for the Safeguarding Taskforce Report it became clear that there was a heightened level of anxiety from parents that what happened to Ann Marie Smith could happen to their child. Following on from the work undertaken by the Safeguarding Taskforce the Minister for Human Services, Michelle Lensink requested an extension of the safeguarding work to include issues such as Case Management, Community Visitors Scheme, Supported Decision Making, Circles of Support, Trust Arrangements and Community Guardians. In September 2021 the Disability Advocate presented an issues paper on futures planning outlining information obtained from families, carers, advocacy agencies and support providers. A number of common themes and potential solutions have emerged that require further exploration.

#### Methodology:

The method used will be to gather information from through meetings with families, advocates, and service providers using the following questions as a starting point.

The following questions will be formatted to enable those people who are unable to attend meetings to be able to be involved by responding in writing.

A report with findings and recommendations will be made and presented on 17/12/21.

A number of questions will be canvassed:

Question 1: How can parents make provision for their son or daughter with a disability so that they will be well cared for after the parents are no longer around?

Question 2: Who can be relied upon to care that a person with a disability is OK if parents are too frail or have passed away?

Question 3: What role do circles of support play in future safeguarding of people with disabilities?

Question 4: What role can siblings play when parents are no longer around and what supports might they need?

Question 5: Should capacity building grants be available through the NDIS Information Linkages and Capacity Building Program to provide information and training on future planning initiatives?

Question 6: What value do you see in the development of a Personal Support Service in SA?

Question 7: Do you support use of Special Disability Trust or a Memorandum of Intent?

Question 8: What value do you see in individual advocacy services?

## 11. Glossary

This glossary is a list of commonly used acronyms or terms throughout the report.

<b>ACRONYM</b>	<b>FULL TITLE</b>
ASID	Australasian Society for Intellectual Disability
CALD	Culturally and Linguistically Diverse
CVS	Community Visitor Scheme
DACSA	Disability Advocacy and Complaints Service SA inc.
DHS	Department of Human Services
ILC	Information Linkages and Capacity Building
NACBO	National Alliance of Capacity Building Organisations
NCID	National Council on Intellectual Disability - Inclusion Australia
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PSS	Personal Support Services - Future Living
SACAT	South Australian Civil and Administrative Tribunal
SACID	South Australian Council on Intellectual Disability
SALRI	South Australian Law Reform Institute

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