



**Submission from Our Voice SA about the  
NDIS Supporting you to make your own decision Consultation Paper**

10 September 2021

To Whom It May Concern,

We are writing to you on behalf of Our Voice SA (OVSA). OVSA is a self-advocacy group for adults living with intellectual disability. Members of OVSA speak out about matters that impact on people living with intellectual disability.

OVSA provides training in self advocacy and ensures the voices of South Australian's living with intellectual disability are heard. Members of OVSA meet for regular peer support meetings to discuss matters that impact on people living with intellectual disability. OVSA regularly offers advice to politicians, government officials and the NDIS either on their request or on matters that concern people who live with an Intellectual Disability.

The members of OVSA wish to make a submission to the NDIS Supporting you to make your own decisions Consultation.

The following information has been gained through a series of Peer Support network meetings, focus groups and training workshops over the past twelve months. Many of the comments are direct quotes from OVSA members.

**OVSA members have offered the following information in relation to the consultation questions provided: in Appendix A.**

**1. How can we help people with disability to make decisions for themselves?**

OVSA members want to be included in all decisions that affect their lives. For example, when choosing where they live they do not want to be placed in accommodation just because an agency has a vacancy to be filled. They want:

- to be near accessible public transport so they can visit family, friends and attend regular social activities.
- to live near their chosen social clubs and/ or churches or other activities they enjoy
- to be near a large shopping centres.
- to be near health supports.
- more affordable and accessible housing options to become available throughout South Australia.

In particular they want to be given choices about who they live with and to make sure they are compatible as many tragic stories have been told by OVSA members of the horror of their everyday lives due to having non-compatible housemates with no common interests and of living in domestic violence situations or in situations where they never felt or still feel unsafe.

Many members of OVSA are living independently in the community and have stated they are happy with their living arrangements. Many previously lived in group homes, boarding houses or institutions and they are relishing their current independence.

There are OVSA members who are currently still living in group homes being supported by various agencies. All but one of these individuals has commented on how unhappy they are with their current living arrangements.

Incompatibility is the number one concern for these individuals. They have all stated they were given no introductions to their new housemates prior to being offered their placement. The one OVSA member who states she is happy living in a group home is living with two young women who are in their thirties and who have no verbal communication skills. This woman is 70 years old and lived in an institution for 52 years from the age of 6 years to 58 years. The staff in her group home are the reason she is so happy. They have ensured that she has the main bedroom with her own bathroom and walk in robe and because she is very social, she goes out most days of the week. Staff ensure she has 1:1 support for all her own banking, shopping and cooking using “Active Support strategies”. This woman volunteers with meals on wheels one day a week and works in an Op Shop on a further day per week. She attends day options on a further two days a week undertaking some of her favorite activities. She is an OVSA board member and attends all peers support, focus groups and social functions run by OVSA. This woman constantly praises her staff – for her, living in this same group home for the past twelve years and having staff who have great values and who she relates to and who meet her needs (and in comparison, with her previous unhappy life in an institution), means that she honestly says she is happy, and she has stated that she does not want to move.

Other issues raised by OVSA members around living in a group home are lack of choice and control (i.e. the ability to make decisions for themselves) around types of meals and

mealtimes, snacks, shopping and banking. They state that support staff will at times go to the bank for them or go shopping without them.

They have also mentioned they are not able to decide when they shower or wake up due to staff routines and rosters.

“Some people want to live on their own and some want to live with others. It is all choice in your life. People in the community care, they don’t know what is going on. They don’t know how some people who live with a disability are being treated. We need to let them know so they can support us to choose who we live with and choose who support us. We need to talk on radio stations and T.V. and YouTube and explain what it is like to live with a disability and let the general community know our stories. We could march in the city or have a day of awareness, a day of self-advocacy and say “Hello, we are here. We need to go into mainstream schools and teach the kids about disability; how to treat us- it is easier to speak with kids rather than adults.”

-Quote from an OVSA member

Below are some examples of OVSA members’ experiences:

- A middle aged articulate female OVSA member lives with three older men who do not have any verbal communication and who have nothing in common with her. She has requested for the past three years to move out into her own home and live independently but has been told by representatives from her agency this takes times. She has recently had an OT Assessment to establish her individual needs for future independent living, however she has been told this move will still take years to achieve. She is very frustrated with her living conditions and the time it is taking for her goal to be achieved.
- A male OVSA member lived independently for ten years and then lived with his wife for 20 years; when he separated from his wife he did not enjoy living alone. He requested to live with someone else for company. An agency offered him a place in a group home. He was not introduced to any of his current housemates prior to moving. He has been living in his group home for four years and he is very unhappy. He has stated: “I have lost my independence. I have nothing in common with my housemates. I can no longer see my family doctor or local chemist who knew me well, the staff say this is due to distance issues. I don’t get to choose my own meals and I am expected to eat my lunch and dinner at the same time as my other three housemates. They had a slot for me, a vacancy, and they put me in it and I feel I am there helping to pay for the others to have a good life.” This man has had no luck in getting a change of circumstances over the past four years even though he continues to raise his concerns with the agency and his family. OVSA has suggested that he ask for an independent advocate to support him.

Below are quotes from OVSA members about not being able to make decisions for themselves:

- “Since I moved into supported accommodation, I have lost my independence. I am not allowed to go for a walk on my own.”
- “We need to make my own choices. Without choices there are tragic circumstances for people.”
- “I want to continue to see my family Doctor. Staff make me go with them and my housemates all together to see a local doctor. They say it is quicker if we all travel together in the same car and have appointments at the same time. They make me do the same to pick up my medication from the chemist.”

**2. Who are the best people to help you (or a person with disability) to make decisions?**

**3. What should they do to help with decision making?**

**4. How can they get better at helping?**

OVSA members have stated they would each like an Independent Advocate to support them to make decisions. They do not want anyone who is attached to an agency and on most occasions, they do not want family to support them to make decisions (due to family often being over protective).

**5. How can we make sure the right people are helping? For example:**

- **that they are building the capacity of the person with disability**
- **that they are considering what the person with disability wants.**

As above, OVSA members believe the person who is “walking alongside them and has their back” should be totally independent to any agency and not be a family member.

There have been issues that OVSA members have faced around who supports them:

- It is common for members to have numerous changes in Support Coordinators via their NDIS Plans. This is frustrating for members who find themselves constantly having to tell their stories and state their needs repeatedly. Sometimes these Support Co-ordinators are based interstate and do not understand the needs of the individual, or the changes required to meet their needs in their home.
- One OVSA member has waited over three years for his NDIS plan to approve a wheelchair and during this time he has struggled to maintain his independence due to his current health needs including severe breathing issues. He has only had access to a walker. It has not helped that he has had four Support Coordinators during this time.

**6. Can you tell us about a time when someone helped you (or a person with disability) to make a big decision? What worked well? What could have been better?**

One OVSA member, who is in her early twenties, lives in a group home and is supported by around 20 staff on a 24-hour active roster due to her high physical support and health needs. She lives with Muscular Atrophy and requires support for all her daily living tasks. Two of the staff on these rosters do not meet her needs adequately due to their general lack of empathy, inappropriate comments, at times rushing during her showering and dressing routine which makes her feel unsafe, and they both have poor attitudes. She does not want to be supported by these two staff members anymore as it is affecting her mental and physical health. The management of the agency who support her are aware of these staff and their issues but continue to allow them to work with very vulnerable people. After getting advice from another OVSA member and with the help of her new support coordinator, this woman has recently been able to employ some external support staff to take her on outings on weekends, as previously she was often left in her room for many hours alone. This recent acquisition of external staff has given her hope for the future that she may be able to request these two support workers, who work for the agency who supports her, are no longer employed to work with her. This woman also now has an independent advocate to walk alongside her when she voices how she feels. She has made a meeting with Management of the Agency who supports her to bring up how she feels about a number of issues and her Independent Advocate will be at her side at the meeting to support her.

OVSA members have stated:

- Having an Independent Advocate is so important for individuals, especially when being supported through agencies. South Australia does not invest enough funding in independent agencies who employ independent advocates. Our Voice SA has previously written to Ministers and Government officials about this need.
- Having each other as a member of a peer support network has also helped OVSA members as they share their experiences and that gives other members ideas and possible solutions to their problems.
- “It is important to keep peer support groups/training in self- advocacy, human rights and decision making and conferences and workshops going, we support each other and learn to speak up for our rights. Sometimes negative things happen where I live. You have to have a voice. I am now more confident, and I speak up for myself. What do we do for people who don’t have a voice?” – OVSA member
- “Sometimes people say to people who have a disability “You are useless, you are no good” and they lose their confidence. How can we support those people to have a voice? They need independent advocates and to join peer support groups like us.”

## **7. What should decision supporters know about so they can help people with disability make decisions?**

They should have training to ensure they know that their role is to support the expressed wishes of the person and not be influenced by the interests of agency staff or family.

Ensuring staff who work in community homes and other areas of support have appropriate training in meeting the individual needs and listening to the choices and decisions of someone who lives with a disability. (Perhaps all support staff should have to be accredited annually in the same way Nurses, Teachers and Developmental Educators).

Below is a quote from an OVSA member:

“I am a self-advocate now and I want my friends and other people to know they have rights. I want to help my peers to advocate for themselves like I am doing now. In the past I did not feel safe, as I was abused by my partners – No one ever taught me about relationships when I was young. I did not know how to choose a boyfriend that was good for me or how to stick up for myself. I know people I can talk to now but I did not have anyone to talk to in the past. It is important that people with a disability have someone they can talk to and someone who knows what they are talking about. With NDIS many of my friends do not know who to talk to. They used to have a case manager that knew them, but that is gone. They say they can't reach people when they phone their NDIS support person or that they don't see them often or they don't phone back. I have people I can ask now. Being a part of Our Voice has been so good for me. Everyone should be able to attend something like I do; but it costs money for travel so the NDIS need to give people enough money to get to the meetings. Everyone needs to know their rights and have good support. Someone they can ask about anything they want and get help when they need it. They should be able to get information and also have the information explained to them especially if they cannot read and write. The NDIS need to make sure every person with a disability has someone they can contact just for them that knows what they are doing and will help them when they need it. Sometimes family want things that the person with a disability does not want, they need someone they can talk to outside of family and support staff to talk about things they want or something they are not happy with. I have that now, but I did not have it before.”

## **8. What is the best way to support people with disability to make decisions about their NDIS plan.**

## **9. Are there different things to consider for people with different disabilities or cultural backgrounds?**

## **10. How can we help reduce conflict of interest?**

## **11. How can we help reduce undue influence?**

The following information and ideas are presented as answers to questions 8 to 11:

Many members of Our Voice SA have highlighted they do not have the confidence or courage to speak up when their agency staff (or even some family members) are present at their NDIS Planning meeting. They feel they would like to have a meeting prior to their planning meeting where they can say how they truly feel and have this documented in preparation for their NDIS planning meeting.

**Conflict of interest experiences of people who live with a disability in regards to their NDIS Goals not being heard prior to and at their NDIS Planning Meetings:**

- A 50-year-old woman who wants to live in her own unit/home or in her own unit in a cluster site: this has not been recorded in her NDIS Goals even though she has constantly stated this is her expressed wish.
- A 40-year-old man who does not want to do his own cooking or housework; he would rather pay for frozen meals and pay for a cleaner to come in once a fortnight; his NDIS Goals state that he wants to learn to cook and do his own housework; he said he felt pressured into agreeing to this by his Agency staff (Team Leader and support staff) who attended his planning meeting.
- A woman in her 50s who had asked for many years to have a say in who she lives with as she had been placed with housemates who hit her constantly or kept her awake all night screaming as they had mental health issues; she was moved four times over an 18 year period and was given no choice of who she lives with on each occasion; she did not even get to meet her new housemates prior to moving. She has recently met with and approved her current housemates and accommodation and she is finally happy with the outcome. This only occurred as she was told about a vacancy within in a house in another agency that a friend thought would suit her; she arranged to visit this house and meet the people who lived there; she could tell it would suit her and she then fought to be considered for this vacancy and to move agencies.
- A 22-year-old woman who was living in a domestic violence situation with her housemate due to incompatibility. She was confined to her bedroom and lounge area for much of her day as she was afraid to enter her kitchen when her housemate was home. The agency would not listen to her until she got an external advocate involved.
- A 57-year-old male who has been living in a domestic violence situation with his housemate for over three years. His family have been meeting with the agency on a regular basis to try to resolve this issue and they have had no assistance with help- until they threatened they were going to take the situation to the NDIS Safeguarding Commission. The Agency has now promised to move the person within a three-month period of time.
- A 60-year-old woman who lived in an institution all her life because her family would not let her move to the community. When her mother died her sister finally agreed for her to trial a community setting. She has now been living in a community setting for ten years and she has just turned 70. She loves her new home and life; unfortunately the sister is still receiving negative comments from other family members who did not wish their sister to move to a home in the community.

**The idea is to introduce a Pre- Planning Process prior to the NDIS Planning Meeting – This Pre-Planning Process for Individuals who live with an Intellectual Disability will involve Planners who also have an Intellectual Disability and who have received Intensive Training to undertake this role to support their Peers. This meeting could also involve an Independent Advocate, if the Individual has one, being present at the meeting and anyone else who the individual feels comfortable inviting to their pre- planning meeting.**

**Aims are to:**

- Minimise a conflict of interest in the NDIS process
- Ensure individuals who live with an Intellectual Disability are able to articulate their EXPRESSED WISHES at their NDIS Planning Meeting(s) rather than others planning for them in their BEST INTEREST
- Support people who live with an Intellectual Disability to live an ordinary life
- Support people who live with an Intellectual Disability to make their own decisions
- Ensure people with an Intellectual Disability are given the same opportunities as others, (something which was almost impossible to achieve before the NDIS.)

**Background Information: (NOTE: This background information is extracted word for word from the NDIS Opportunities and Understanding Workshops).**

Information and support is needed at every stage of the NDIS Process. This information and support needs to come from an independent source that is free from conflict of interest; for example service providers or families

- What happens when your goals are different from the those of your parents/family member/service provider?
- What happens if a service provider strongly encourages a person with disability to include their services in an NDIS plan?

To get ready for an NDIS meeting, people with a disability need to do a bit of preparation:

- This thinking and preparation is one of the best ways to make sure the NDIS First Plan is a simple and quick process
- Thinking about a good life for the next NDIS Plans
- After doing research and gathering ideas about how the person with disability wants their life to be like, it is important to properly articulate their goals.

It is very important for the person with disability to know they can bring along people of their choice to the Planning Conversation if they wish to do so. Competition is very important to the success and longevity of the NDIS, and this is an important reason why minimising conflict of interest is a good idea.



**Recommendations:** It is proposed that a Team of existing **Our Voice SA** members ( **or similar advocacy groups in other states of Australia**) be developed from those individual members of **Our Voice SA** who have already received training to become Peer Supports and who wish to volunteer their services to support other Individuals who have an Intellectual Disability to ensure their wishes are heard and acted upon at their NDIS meeting(s). This Team of individuals will be trained to ensure they have the skills to explore the expressed wishes of an individual who has an Intellectual Disability: These Expressed Wishes will explore every aspect of the person who is living with a disability's life. **Trained Individuals from the Our Voice Team** will support the Individual who has an Intellectual Disability to put their expressed wishes in writing in readiness for their initial NDIS Meeting / Review Meeting or their NDIS Change of Circumstances meeting. This signed Document/Agreement would be utilised at the Individuals NDIS meeting as a base line for their agreed NDIS Goals.

**Funding Requirements for this to occur will include:** Funding for a Project Trainer who is skilled and has experience in Train the Trainer workshops/Individual training in how to gain expressed wish from Individuals who live with a disability. Funding for the Peer Support Trainees to have access to paid Secretaries/Scribers who would document this information in a participant's Agreement (including an easy read Document/Agreement if required) ready for the participant's signature. Funding may be required for a Translator or a trusted paid support worker/family member/friend etc. to support the interpretation of the persons mode of communication. Funding will be required for an Evaluation of the Project.

**The areas of the participant's life that would be explored to gain their expressed wishes during the Planning Process would cover every aspect their life: e.g.**

- **Accommodation:** what type of accommodation would you like/ what would that accommodation look like e.g. how many bedrooms does it have; does it have a big kitchen/ a bath/ a billiard table; would you have pets/ what type of pet / who would you like to live with or would you like to live alone/ where would you like to live etc.
- **Health:** (including Diet)- are you eating the foods that you like/ what do you like to eat/ are you happy with your weight/ Exercise- Do you exercise/would you like to join a gym/ do you swim/so you walk/ would you like to swim or join a walking group. / Mental Health/ Do you ever get anxious/ Do you have someone you can talk to if you do get anxious/ Are you on medication/ Do you have a regular Doctor/Do you get on well with your Doctor or would you like a different doctor; would you like to choose between a male of a female Doctor/ Are you on medication /Do you know why you are on the medication you are prescribed and what are their side effects etc.
- **Lifestyle:** (this includes where you want to work/or attend a day option/how you want to have fun and who you want to have fun with e.g. what activities do you enjoy or what activities would like to try/would you like a holiday and if so where would you like to go and who would you like to go with on your holiday/what type of relationships you would like in your life. What is your preferred method of communication? Tell us about your communication needs and how we can support others to communicate with you. Do you feel your social needs are being met/ Do

you feel you are participating in your community/Do you feel you are supported with community inclusion etc.

- **Finances:** Are you happy with your current situation; do you know where your money comes from; do you have a bankcard/ would you like a bank card/ do you manage your own money/ would you like to manage your own money or some aspects of your own money/ do you feel you have enough money to do the things you enjoy in life e.g. go out to a restaurant for a meal/ café for coffee and cake/ go bowling/go to the pictures/ save for a holiday/ purchase your own car or your own house etc.

**12. What are your concerns (if any) around people with disability being more involved in Making decisions for themselves?**

N/A

**13. What else could we do to help people with disability to make decisions for themselves? Is there anything missing?**

Please refer to our responses above.

**14. Do you have any feedback on our proposed action in Appendix C of this paper?**

The Proposed Actions in Appendix C are comprehensive and inclusive of people who live with a disability.

Please feel free to call us on 08 8373 8327 or 0433 436 256 if you have any questions about this submission.

Kind regards

**Debbie Knowles** (Project Leader, Our Voice SA) and **Alison Vivian** (Project Officer, Our Voice SA)

**(On behalf of Ian Cummins and the members of Our Voice SA.**