Stronger and Louder

Exploring the emerging priorities of South Australians living with intellectual disability

OUR VOICE SA

Participation + Rights = Power

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About this report

Purpose

Our Voice SA wanted to develop a future outlook for their work across South Australia. With funding through the National Disability Insurance Agency (NDIA), Our Voice SA conducted a needs analysis to better understand the emerging priorities of South Australians living with intellectual disability, particularly within the National Disability Insurance Scheme (NDIS) landscape.

By conducting the needs analysis, Our Voice SA identified a number of gaps in access to information, knowledge and understanding of the NDIS and access to the community. This report was written to enable Our Voice SA to share these findings and make recommendations for key stakeholders including the NDIA, South Australian state government, local council, service providers and other key decision makers.

Our Voice SA

Our Voice SA is a peer-led self-advocacy organisation for adults living with intellectual disability.

Our Voice SA became an incorporated body in 2007 and currently has 70 members living with intellectual disability and 30 associate members including family and friends of people living with intellectual disability. Membership is growing and the group is reaching out to others in SA living with intellectual disability and their families on a regular basis. The group is expanding into other suburban areas and country regions with a view to empowering people living with intellectual disability to become self-advocates and peer supports for each other.

The Our Voice SA Board and Peer Support Group currently meets once a month to talk about issues important to them. The members of Our Voice SA all have different abilities and believe that difference is good. Our Voice SA speaks out about matters that are important such as having a voice and extending peer networks. Our Voice SA has its own website and Facebook page.

Our Voice SA is supported by JFA Purple Orange which, as a host agency, currently provides support via a Project Leaders time, the provision of meeting space and financial management. JFA Purple Orange is a not-for-profit agency that develops and promotes social policy and practice solutions in response to the aspirations and issues reported by people living with disability.

Our Voice SA is reaching out to other South Australians living with intellectual disability to ensure that they have access to accurate, understandable information about the NDIS and to provide good quality peer-support and self-advocacy training.

Contents

Summary

Our Voice SA wanted to develop a future outlook for their peer-led self-advocacy work across South Australia. With funding through the NDIA, Our Voice SA conducted a needs analysis to try and better understand the emerging priorities of South Australians living with intellectual disability, particularly within the NDIS landscape. This report provides an analysis of what people told us about their current and emerging priorities and what would assist South Australians living with intellectual disability address those priorities.

To ensure that the voices of people with intellectual disability were central to the process, Our Voice SA recruited two people living with intellectual disability to form a co-design group. The responsibilities of the group were to design the project, develop interview questions, design marketing and promotion strategy and develop final recommendations in the report.

Our Voice SA developed two electronic surveys (see Attachment A and B) across nine themes identified through co-design. Our Voice SA noted that collecting information through online surveys is not accessible for some people living with intellectual disability who do not have the required literacy or computer skill. In response we also conducted one-on-one interviews and small group consultations. In total, 40 people across regional and metropolitan South Australia provided input into this research, including 28 people living with intellectual disability and 12 family, friends or paid workers.

All respondents said they have a NDIS plan. People living with intellectual disability reported that information about the NDIS was often not given in ways that they could understand and this resulted in having limited understanding of the NDIS or NDIS processes. Family, friends and paid workers identified parts of the NDIS that made things more difficult including rigid time lines, administrative heavy processes, not enough funding, frequent changes at agencies, invoicing agencies, delay in plan approvals, management options leading to limitations and NDIS misunderstanding the needs of the individuals.

People living with intellectual disability also reported having difficulty connecting into community, with a lack of transport identified as the biggest barrier. Other barriers to accessing the community were having inclusive places to go, not knowing how to access places and mobility issues. Family, friends and paid workers also said that travel expenses, lack of funds to provide adequate support for outings and perceived safety as barriers to accessing the community, places or events for people living with intellectual disability.

While all participants that lived in their own home or with family stated they were involved in decisions about where to live or who to live with, only one of the participants who lives in a shared or group home had a say in where they live or who they share their home with. People living with intellectual disability in regional areas stated that accessible housing was not always available, making the ability to move difficult.

Seven (17%) participants indicated they have difficulty using public transport and needed support present to access public transport. Accessibility and not feeling safe on public transport were the areas highlighted as barriers for people living with intellectual disability. Public transport was not readily available to the people from regional areas. Most people reported that they rely on the community bus service which has limited scheduled runs, taxis or family and friends to travel between towns.

People living with intellectual disability reported that they need information shared with them in various formats including Easy English, video, text to speech, role play, visual representation, verbal communication and having support to go through the information with another person. Barriers to accessing information to make decisions include low literacy skills, complexity of information, information only being available in written formats and not having skills or access to use computers.

All respondents were asked to identify what their number one priority or issue would be for the intellectual disability community. From their responses, three main themes of priority were identified;

▶ **Access**

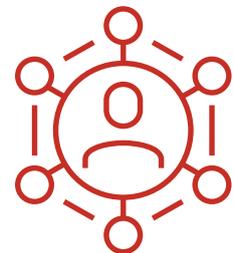This includes access to information, the community, places and services;

▶ **Inclusion**

This includes having their voices heard and disability awareness within the wider community, particularly medical staff.

▶ **Choice and decision making**

This includes having opportunities to make choices about their staff, services, daily activities, housing and transport.

Recommendations

This research has highlighted a number of gaps for people living with intellectual disability in SA and Our Voice SA has made the following call to action as priorities for key stakeholders:

1. All information about services in South Australia must be in multi-modal accessible formats, including video, Easy English, audio and verbal communication.

2. The NDIA should provide fully accessible multi-modal resources and increased support for people living with intellectual disability to understand and implement their NDIS plan and to challenge it if they don't like it.

3. Key government decision makers and service providers must take the time to listen to people who live with intellectual disability. This could be achieved through mechanisms such as 1:1 interviews or small focus groups.

4. NDIA should continue funding peer networks and individual capacity building activities that are designed by and for people living with intellectual disability which focus on building the self-advocacy and decision making skills of people living with intellectual disability.

5. South Australian state and council authorities should consult with with Our Voice SA and other stakeholders living with intellectual disability about what makes community accessible to inform the development and implementation of their Disability Access and Inclusion Plans.

Methodology

To ensure that the voices of people with intellectual disability were central to the process, Our Voice SA recruited Nadia Field and Bradley Bettens, two people living with intellectual disability to form a co-design group. The responsibilities of the group were to design the project, develop interview questions, design marketing and promotion strategy and final recommendations in the report.

The co-design group decided that the interview questions would span across 9 themes:

1. National Disability Insurance Scheme (NDIS)

2. Accessible places, events and community

3. Decision making, choices and being in control

4. Relationships

5. Safety

6. Housing

7. Employment

8. Transport

9. Accessible information.

The co-design group met twice during the project.

Our Voice SA developed two electronic surveys (see Attachment A and B) about these 9 themes and these were shared through Our Voice SA's online networks, one for people living with intellectual disability and one for family, friends and paid support. The Our Voice SA Project Leader and Project Officer also conducted five individual 1:1 interviews. Four regional group consultations were also run by the Project Officer in Kadina, Port Augusta, Mount Gambier and Minlaton.

Data was de-identified prior to data analysis. All data has been stored confidentially and will be reported in a way that ensures identification of participants is not possible. Participants were able to choose which questions they wished to respond to, and could elect to exit the interview at any time.

Demographics

Response totals

Response Type	Online Survey	1:1 Interview	Group Consultation	Total
PLWID	5	5	18	28
Other	12	0	0	12
Total	17	5	18	40

People living with intellectual disability (PLWID)

How PLWID responded (N=28)

Online Survey	14
1:1 Interview	10
Group Consultation	4

Gender (N=28)

Male	17
Female	11

Age (N=28)

18-34	5
35-54	5
55+	18

Location (N=28)

Urban	7
Regional	20
Unknown	1
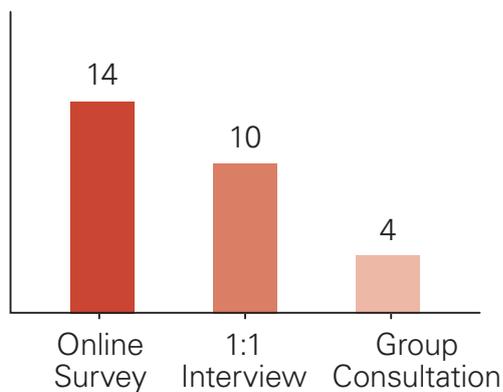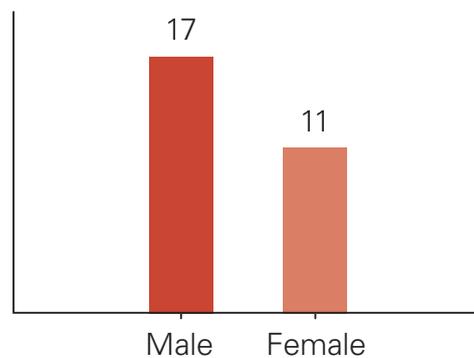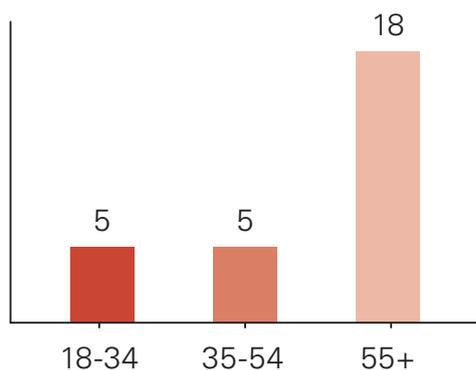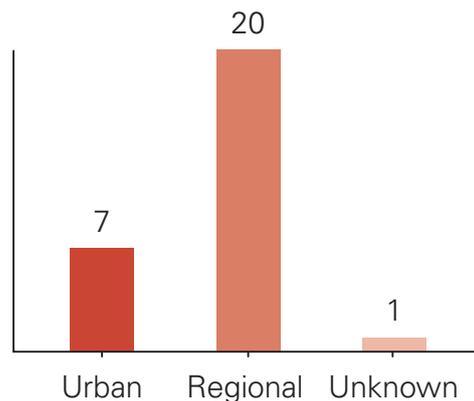
Family members, friends and paid workers

How family, friends and paid workers responded (N=12)

Category	Value
Online Survey	12
1:1 Interview	
Group Consultation	

PLWID Gender (N=12)

Category	Value
Male	10
Female	1
Both	1

PLWID Age (N=12)

Category	Value
18-34	7
35-54	4
55+	1

PLWID Location (N=12)

Category	Value
Urban	11
Regional	1

Sources (N=12)

Category	Value
Family	8
Friends	1
Paid Workers	3
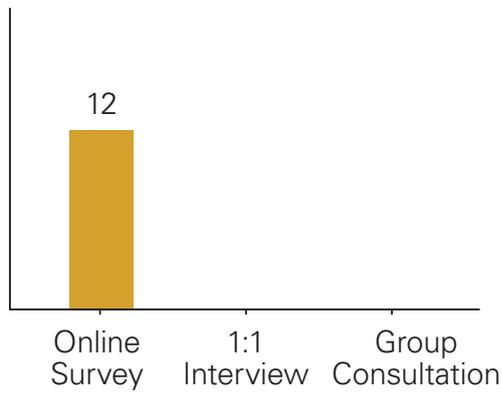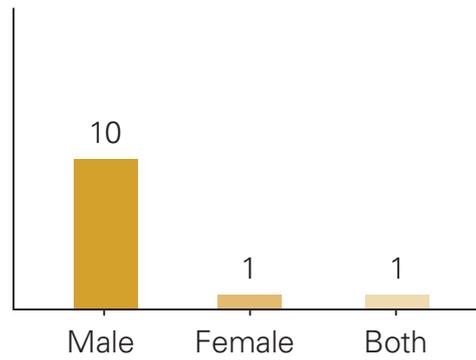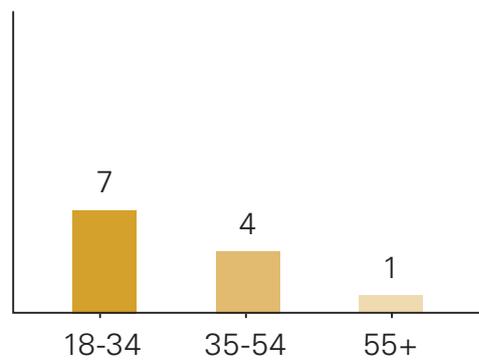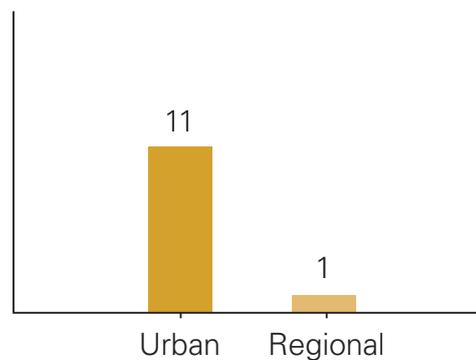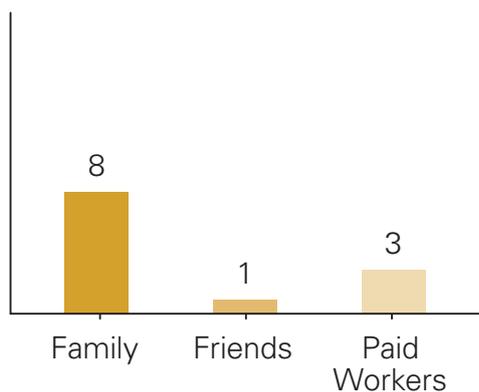
Findings and recommendations by theme

Results from the online surveys, 1:1 interviews and regional group consultations.

1 NDIS

All of the people living with intellectual disability who answered the survey, interview questions or participated in the regional consultations have a NDIS plan. All of the survey responses completed by family, friends and paid workers about people living with intellectual disability have a NDIS plan.

NDIS Information

Information provided to people living with intellectual disability about the NDIS came from service providers, family members, NDIS, Disability Advocacy Agencies and local government. Over 80 per cent of the participants (33 people) reported that information about the NDIS was not given in ways that they or the person living with intellectual disability could understand. People living with intellectual disability identified having limited understanding of the NDIS or NDIS processes, continued changes or updates to the plan, too many people speaking for them and difficulty communicating with the NDIS as barriers to being able to access or navigate the scheme. Family members also stated that not having adequate understanding of the NDIS made the scheme confusing, complex and overwhelming.

> "Change of circumstances was a nightmare. It was difficult to get a meeting and impossible to get an adequate new plan"

Additional information or resources in easy read were identified as ways to overcome some barriers. This included NDIS plans written in simple language, with the NDIS giving simple examples to assist individuals make choices.

Other suggestions included an increase in support coordination available to people living with intellectual disability, sharing experiences from different perspectives through peer networks such as OVSA, development of specialist support to guide people in using their plans, and extra NDIS staff to go to individuals and explain their NDIS plan once it is approved.

NDIS Plans

The majority of individuals who completed the survey did not know what was in their plan or were unsure about the contents of their plan. Only three people stated they knew what was in their plan, only one stated that they knew how to implement their plan. Almost all of the participants (38 of the 40) receive formal or informal support from family, NDIS providers or through support coordination.

Additional support to implement plans, plans that are easier to read and understand, training on the NDIS, information about the NDIS that is easier to understand and plans that are easy to navigate were all identified as ways to support people living with intellectual disability to better understand and use their NDIS plans. Family members also identified that they would like training about the NDIS, simpler language in plans and more flexible plans to allow for emergency circumstances.

> "Documents with less words would help a person with intellectual disability to understand better. Maybe a simple question and answer sheet for them to be aware of things they need to think about"

NDIS Satisfaction Scale

Participants who completed the online survey and 1:1 interviews were asked to rate the NDIS on a scale from 1-10 where 1 is the worst and 10 is the best. The average score from the 22 responses was 6/10.
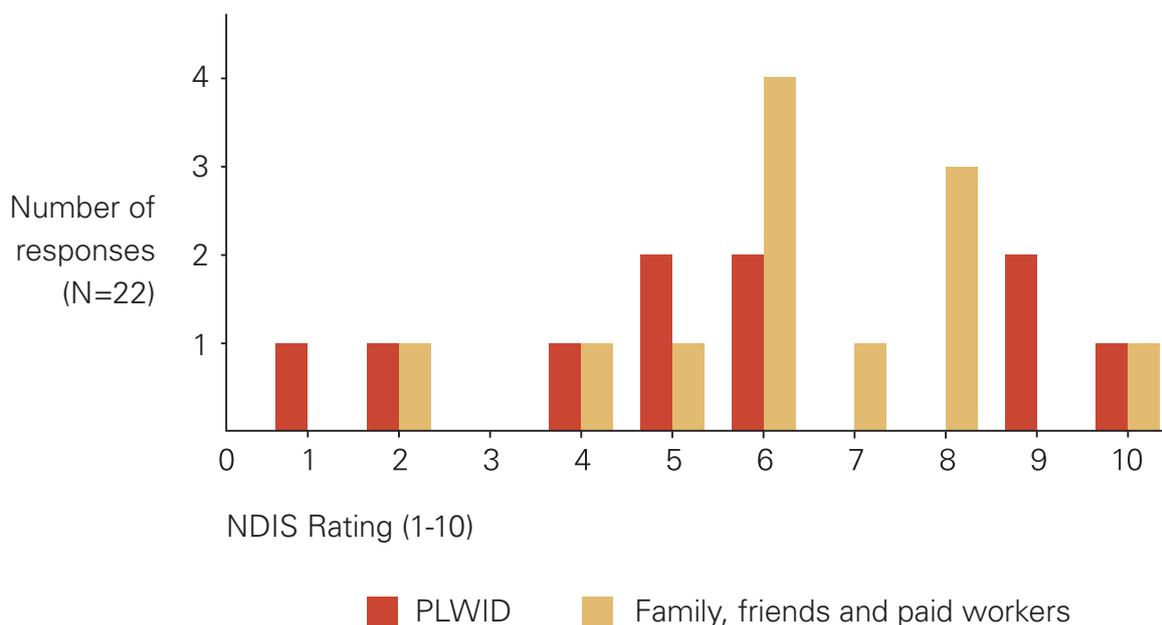
Positive responses about the NDIS from people living with intellectual disability included gaining access to equipment, community participation, access to leisure and recreation activities, having new opportunities and moving into a new home.

> "I am in my new home"

Family, friends and paid workers saw increased access or new access to allied health services, having choice and control of support, having more choices about recreation and employment, flexible support options, support workers to help follow up on therapy as positive outcomes from the NDIS.

"The right to choose non-disability agencies."

Participants provided examples of goals that have been achieved through the NDIS including meeting new people, getting out, having meaningful days, going on a holiday, increased independence, improved speech and language skills, improved daily living skills and increased social connections.

Negative responses about the NDIS from people living with intellectual disability included limited access to information or not being able to understand the information received, delays from NDIS, not having a regular person at the NDIS to contact with questions and not enough funding or hours to meet goals.

"I don't feel I can say no"

"No person to go to in the event of any query"

Family, friends and paid workers also identified parts of the NDIS that made things more difficult including rigid time lines, administration heavy processes, not enough funding, frequent changes at agencies, invoicing agencies, delay in plan approvals, management options leading to limitations and NDIS get information about an individuals needs wrong.

"The process is based on a deficit model which is difficult and feels yucky"

"Having to prove our family member has a disability then having to fight (unsuccessfully) for the support required"

Overall, the findings indicated that while some NDIS participants had experienced greater choice and control and had achieved some goals, others indicated that information about the NDIS was hard for people living with intellectual disability to understand and provided in formats that were not accessible. It was also found that people living with intellectual disability had limited understanding of NDIS processes including what was in their NDIS plan and implementing their plan. These findings demonstrate the need for all information to be in accessible formats such as video, Easy English, audio and verbal communication. As well as accessible information people living with intellectual disability require increased support to understand and implement their plan and to challenge it if they don't like it. This means having an unbiased support person to explain things, in the spirit of supported decision-making where the person is supported to make their own informed choice, not just putting an easy read version up on the website.

2 Accessible places, events and community

Over 50 per cent (insert the numbers here too) of people living with intellectual disability reported having difficulty going into the community. Lack of transport was identified as the biggest barrier. Other barriers to accessing the community were not having inclusive places to go, not knowing how to access places and mobility issues. While there were many barriers reported, all participants said that community access had either stayed the same or improved since the introduction of the NDIS.

Family, friends and paid workers also said that travel expenses, lack of funds to provide adequate support for outings, the individual's capacity to plan things independently, the individual skills learnt have not been transferred to other environments (travel by public transport) and perceived safety were all barriers to accessing the community, places or events for people living with intellectual disability.

> "…the community part of the plan is more flexible but with limited access to staff"

People who participated in the regional consultations stated that recreation areas such as swimming pools, cinemas, beaches, sporting events and dining facilities were not accessible to everyone in the community. Some people were required to travel up to an hour and a half for accessible recreation activities as they were not available in their home town. Other barriers to community participation for people living in regional areas were that footpaths, road crossings, street lights and public toilets were often poorly maintained restricting physical access to the community.

The results from the survey and group consultations demonstrate that people living with intellectual disability face numerous barriers to accessing the community including a lack of transport, individual knowledge or skill, lack of accessible venues or insufficient funds to provide adequate support. It is vital that key decision makers listen to people living with intellectual disability about how to make the community accessible. This could be achieved through mechanisms such as 1:1 interviews or small focus groups.

3 Decision making, choices and being in control

Making Everyday Choices

All people living with intellectual disability responded that they are actively involved in making small everyday choices and half are involved in making big changes in their lives. Seven people said they want to move into their own home or change where they are living.

Choosing Support

Over half of the people (29) stated that they don't choose their own staff or the activities that staff perform, staff are either allocated by the support agency or chosen by family. People living in regional areas stated that there is limited choice in support workers due to lack of employees in the area.

| "I'd love a male support worker"

While most participants felt that they had choice and control around small everyday decisions, it was found that many were not provided opportunity to make decisions about big things in their lives such as where or who they live with and who their paid support provider would be. It is important for people living with intellectual disability to be involved at the heart of all decisions about their life including, but not limited to, their housing or support arrangements. One way to increase opportunities for decision making is to provide people living with intellectual disability information in accessible formats and to use supported decision-making frameworks.

4 Relationships

Making Friends

25 respondents reported that they knew how to make friends and 9 stated that the NDIS has helped them meet new people. A lack of NDIS funding to provide adequate support in the community, access to transport, finding people with common interests and accessible places in the community were identified as barriers to making friends and meeting new people

Choosing Groups

80 per cent (33) of respondents reported that they decide what groups to attend and of those, two thirds (21) have been able to keep attending groups or attended new groups as a result if the support provided through the NDIS.

The barriers to joining new groups were inadequate funding support to attend, access to funding for day options, access to transport and monopoly of service provision.

> "The agency managing his accommodation also manages his day activity"

Self-advocacy Groups

Eight people stated that they were part of a self-advocacy group.

The regional participants identified self-advocacy groups as a way for people living with intellectual disability to get their voices heard, talk about topics or issues that are important to the group, learn new things, teach others, an opportunity to meet new people, make changes in their local community and to start changing the perception of disability in the wider community.

> "Joining Our Voice SA has helped me grow, I now have the confidence to speak up about things that matter to me"

Self-advocacy groups, such as Our Voice SA are important to the intellectual disability community as they provide opportunity to share information, meet new people, work together on common issues and to make changes in the local community.

5 Safety

Community Safety

People living with intellectual disability stated that they felt safest in the community during the day, in familiar areas, when with other people or supported by staff. Communication was seen as a major barrier to feeling safe in the community. People said that not being able to express themselves or not being understood by others made them feel unsafe, as did not being able to read.

| "Only feel safe in familiar places"

Other reasons it was thought that people living with intellectual disability may not be safe in the community included poor money handling skills, ability to choose appropriate clothing for the weather, poor understanding and coping skills in social situations, sensory limitations causing safety implications (low sight), limited awareness of strangers and not understanding the social rules of being in the community.

Home Safety

Almost all of the respondents stated that they felt safe at home. One person said they do not feel safe in their home due to their current living arrangements and who they share their home with. Another stated they do not feel safe at home due to the people in neighbouring houses.

These findings indicate that more support is needed for people living with intellectual disabilities to build their skills and confidence to feel safe on their own in the community. Capacity building activities aimed at supporting people living with intellectual disability to be able to access the community, communicate and express themselves may help to reduce safety concerns.

6 Housing

Who do you live with? (PLWID, N=40)
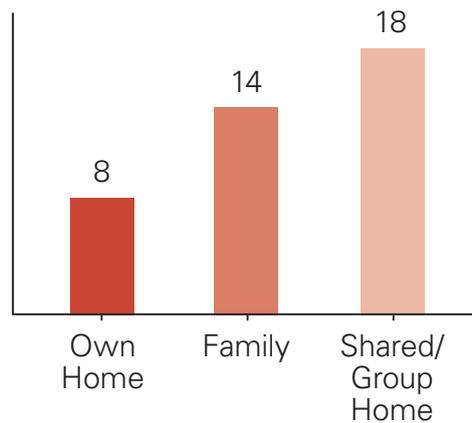
Housing Choices

Participants who live in their own home or with family stated they were involved in decisions about where to live or who to live with. Only one of the participants who lives in a shared or group home had a say in where they live or who they share their home with.

People living with intellectual disability in regional areas stated that accessible housing was not always available making the ability to move difficult. They also stated that the process of moving house took a long time, one individual has been waiting 12 months to move to a new home.

"I want to choose where I live"

The survey results demonstrate that people living in shared or group homes are often not involved in deciding where to live or who they live with. Participants who stated they were involved in their accommodation decisions either lived in their own home or with family. It is important for people living with intellectual disability to be involved at the centre of all decisions about their housing arrangements regardless of their accommodation type. One way to increase opportunities for decision making is to provide people living with intellectual disability information in accessible formats and to use supported decision-making frameworks.

"Some things are decided for me, like if I'm allowed to do certain jobs at work"

7 Employment

Do you work or looking for work? (PLWID, N=42)
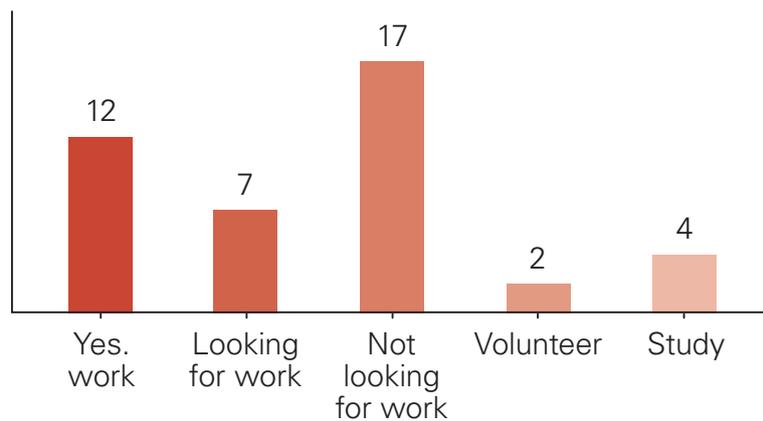
Less than half of the participants were working or studying. Seven of the twelve people who are currently working reported that they work in a supported employment environment. Six people said that they have been able to gain access or make changes to employment or study through the NDIS. Benefits of accessing work or study through the NDIS has been that people living with intellectual disability are part of the community, are engaged and active, have a social connection and supported to remain at the same place of employment.

Seven of the eighteen people who work, study or volunteer feel they can speak up about problems they are facing. Barriers to speaking up included difficulty expressing thoughts, not being given the opportunity to speak up and a lack of confidence to speak up.

People living in regional areas stated that they would like more variety in the jobs available, more say in the type of work they perform and assistance to find employment.

While most participants felt positively about their current employment it was found that some were not able to speak up about problems they were experiencing. Participants face barriers such as difficulty expressing themselves, not being given opportunity to speak up or lacked confidence in their own skills to speak up. While the benefits of employment shared by the participants are important it is also crucial to note that the lack of skill or opportunity to speak up about problems experienced in the workplace has the potential to lead to PLWID being taken advantage of. OVSA provides workshops, mentoring and opportunity to learn self-advocacy skills all of which provide PLWID a platform to address problems in their lives.
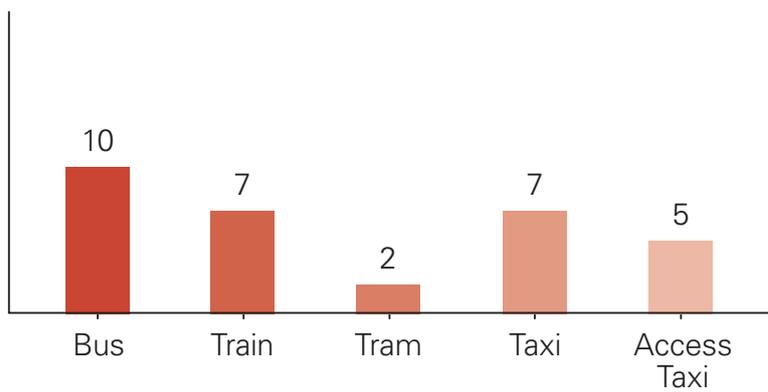
8 Transport

Do you use public transport? (PLWID, N=40)

19	21
Yes	No

Type of public transport (PLWID, N=41)

10	7	2	7	5
Bus	Train	Tram	Taxi	Access Taxi
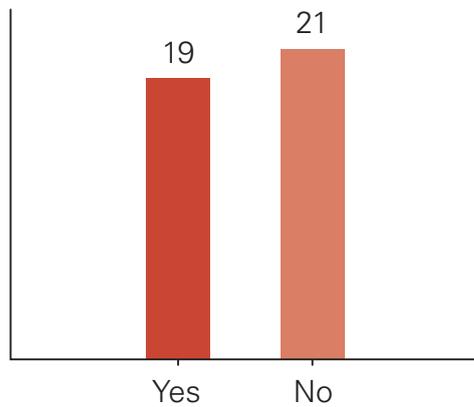
Access to Public Transport

Only 19 of the respondents reported that they use public transport and seven people indicated they have difficulty using public transport and needed support present to access public transport. Accessibility and not feeling safe on public transport were the areas highlighted as barriers for people living with intellectual disability. Two people reported that the NDIS had helped them access transport or increasing access to transport.

| "I can get to day options because they pick us up in the bus"

Public transport was not readily available to the eighteen people from regional areas. Most people reported that they rely on the community bus service which has limited scheduled runs, taxis or family and friends to travel between towns. One regional area does not have a current taxi or bus service running, the day options program has a bus which picks participants up from neighbouring towns each day. Trips to Adelaide for appointments or social gatherings are often made by family or friends transporting individuals or using the coach line that has semi-regular runs throughout the week and weekend.

The survey results demonstrated that the majority of participants do not use any form of public transport, leaving them to rely on family or friends to take them places. It was also found that people living with intellectual disability face a number of barriers when accessing public transport such as accessibility and availability of transport, lack of individual knowledge or skill , limited funds to provide adequate support and individuals not feeling safe when using public transport. More work is needed to ensure public transport is accessible to and used by people living with intellectual disability so they can live more independent lives.

9 Accessible information

Using Information to Make Decisions

Less than half (14 people) of the respondents reported that they could access information to help them make decisions and six respondents reported that the NDIS has made getting information easier for them. Only three respondents said that they could access information about services in a way they could understand.

Barriers to accessing information to make decisions include low literacy skills, complexity of information, information only being available in written formats and not having skills or access to use computers. Those that have not been able to access information about services indicated that NDIS information is too long, information is confusing or difficult to understand and that the individual is unable to contact NDIS independently.

| "Information in a way that I can understand it"

People living with intellectual disability have stated they need information shared with them in various formats including Easy English, video, text to speech, role play, visual representation, verbal communication and having support to go through the information with another person.

Using Online Platforms

27 people living with intellectual disability use Facebook to access information and 13 use websites to access information. Of the responses, only 10 people use both Facebook and websites to access information.

Barriers to using Facebook or websites to access information included low literacy skills, no skills in using technology, not interested in social media, not having access to the internet, and preferring face to face interactions.

> "As a parent I feel like it would be too hard to add in supervising them on Facebook to make sure there were not problems or anything inappropriate"

The findings show that PLWID face a number of barriers when trying to access information to make decisions. It is known that many PLWID have low or no literacy skills and even fewer with computer literacy skills. As demonstrated in the survey responses many of the participants do not use websites to access information. Having access to a computer and internet is fundamental to access much of the accessible information as it is stored on service websites. By ensuring information is shared in multi-modal formats such as video, Easy English, audio and verbal communication we can increase the access for PLWID. It is also important to include hard copies of information and allow time for individuals to go through the information with another person to provide opportunity to ask question or clarify the information being shared.

Main priorities for the intellectual disability community

Individuals, family, friends and paid workers were asked what their number one priority or issue would be for the intellectual disability community, their responses are below. This Needs Analysis has identified three main themes of priority for people living with intellectual disability; access, inclusion and opportunity to make choices.

▶ Access

Access to information, the community, places and services were all identified as priorities in the intellectual disability community. The main priority for people living with intellectual disability is access to recreation activities in the community.

| "Feeling part of it"

Our Voice SA recommends that:

South Australian state and council authorities should consult with with Our Voice SA and other stakeholders living with intellectual disability about what makes community accessible to inform the development and implementation of their Disability Access and Inclusion Plans.

All information about services in South Australia must be in multi-modal accessible formats, including video, Easy English, audio and verbal communication.

The NDIA should provide fully accessible multi-modal resources and increased support for people living with intellectual disability to understand and implement their NDIS plan and to challenge it if they don't like it.

▶ Inclusion

Having their voices heard by others is important for people living with intellectual disability, however disability awareness within the wider community; particularly medical staff, was the main priority.

Our Voice SA recommends that:

Key government decision makers and service providers must take the time to listen to people who live with intellectual disability. This could be achieved through mechanisms such as 1:1 interviews or small focus groups.

▶ Choice and decision making

People living with intellectual disability stated that they wanted opportunity to make choices about their staff, services, daily activities and housing. People stated that choices about transport was the main priority in this area.

| "Never underestimate what people with disabilities can do"

Our Voice SA recommends that:

NDIA should continue funding peer networks and individual capacity building activities that are designed by and for people living with intellectual disability which focus on building the self-advocacy and decision making skills of people living with intellectual disability.

Attachments

ATTACHMENT A **Survey questions for people living with intellectual disability**

1. Your age
   18-34   35-54   55+

2. Your gender

3. Who do you live with?
   Family   On my own   Shared house   Other (please specify)

4. Your Post Code

Theme 1 NDIS

5. Have you got an NDIS plan?
   Yes
   No, not on the NDIS
   No, not on the NDIS but waiting to get a plan
   Unsure

6. Who has given you information about the NDIS?
   Family member
   Service Provider
   Disability Advocacy Agency
   NDIS
   Other (please specify)

7. Was information about the NDIS given in a way you can understand?
   Yes   No   Unsure

8. Do you know what is in your plan?
   Yes   No   Unsure

9. Do you know how to use your plan?
   Yes   No   Unsure

10. Do you get help with your plan?
    Yes   No   Unsure

11. If yes, what help do you get?

12. What has been the best thing about the NDIS?

13. What has been the worst thing about the NDIS?

14. Has the NDIS helped you achieve your goals?
    Yes   No   Unsure

15. If so, which ones?

16. From 1 to 10, where 1 is the worst and 10 is the best, how would you rate the NDIS?

Theme 2 Accessible places, events and community

17. Do you have trouble going out to the community, events or places?
    Yes   No   Unsure

18. If yes, what are the issues you are experiencing?

19. Has going out to the community, events or places changed since the NDIS?
    Got better   The same   Got worse

20. Has the NDIS helped with accessing or increasing access to the community or events?
    Yes   No   Unsure   Not Applicable

21. If no, what has been the biggest challenge?

Theme 3 Decision making

22. Do you make everyday choices like what to wear, what to eat and what do to?
    Yes   No   Unsure

23. Can you change things in your life if you want to?
    Yes   No   Unsure

24. If no, what are the issues you are experiencing?

25. Has the NDIS helped change things in your life if you want to?
    Yes   No   Unsure   Not Applicable

26. If no, what is the main thing you want to change?

27. Do you choose your staff? (Who they are, when they come and what they do?)
    Yes   No   Unsure

Theme 4 Relationships

28. Do you know how to make friends?
    Yes   No   Unsure

29. Has the NDIS helped you meet new people?
    Yes   No   Unsure

30. If no, what has been the biggest challenge?

31. Do you decide what groups you go to?
    Yes   No   Unsure

32. Has the NDIS helped you keep attending groups or join new groups?
    Yes   No   Unsure

33. If no, what has been the biggest challenge?

34. Are you part of a peer network or self-advocacy group?
    Yes   No   Unsure

Theme 5 Safety

35. Do you feel safe in the community?
    Yes   No   Unsure

36. If no, what makes you feel unsafe?

37. Do you feel safe at home?
    Yes   No   Unsure

38. If no, what makes you feel unsafe?

Theme 6 Housing

39. Did you choose where you live?
    Yes   No   Unsure

40. Did you choose who you live with?
    Yes   No   Unsure

41. Has the NDIS helped you make changes at your home?
    Yes   No   Unsure   Not Applicable

42. If no, what is your main priority?

Theme 7 Employment

43. Do you work or looking for work?
    Yes, I work
    No, looking for work
    No, not looking for work
    No, retired
    No, studying
    Unsure

44. If yes, full time, part time, casual, volunteer?

45. If yes, open or supported employment?

46. If yes, how many days do you work in a week?
    1, 2, 3, 4, 5, 6, 7

47. Has the NDIS helped you access work or change things at work?
    Yes   No   Unsure   Not Applicable

48. If no, what is your main priority?

49. Can you speak up at work about problems?
    Yes   No   Unsure

50. If no, what stops you from speaking up?

Theme 8 Transport

51. Do you use public transport?
    Yes   No   Unsure

52. If yes, what type?
    Bus   Train   Tram   Taxi

53. Do you have any problems using public transport?
    Yes   No   Unsure

54. If yes, what are the issues you are experiencing?

55. Has the NDIS helped you access transport or increased your access to transport?
    Yes   No   Unsure

56. If no, what are the challenges?

Theme 9 Information

57. Can you get information about services in ways you can understand?
    Yes   No   Unsure

58. If no, how can information be shared differently?

59. Has the NDIS made getting information easier?
    Yes   No   Unsure

60. If no, what are the main challenges?

61. Do you use Facebook?
    Yes   No   Unsure

62. If no, why not?

63. Do you use websites?
    Yes   No   Unsure

64. If no, why not?

Main priorities

65. What is your number one priority/ issue in your community?

66. What would be helpful to address these issues?

ATTACHMENT B Survey questions for family, friends and paid workers

Please answer the questions about the needs of a person living with an intellectual disability (PLWID)

1. Age
   18-34   35-54   55+

2. Your Gender

3. PLWID Age
   18-34   35-54   55+

4. PLWID Gender

5. Which of the following best describes you?
   Family member/ friend of a person living with intellectual disability
   Service provider
   Other (please specify)

6. Who does the PLWID live?
   Family   On their own   Shared house   Other (please specify)

7. PLWID Postcode

Theme 1 NDIS

8. Does the PLWID have an NDIS plan?
   Yes
   No, not on the NDIS
   No, not on the NDIS but waiting to get a plan
   Unsure

9. Who has given the PLWID information about the NDIS?
   Family member
   Service Provider
   Disability Advocacy Agency
   NDIS
   Other (please specify)

10. Was information about the NDIS is given in a way they could understand?
    Yes   No   Unsure

11. What issues were experienced?

12. What additional information or resources were needed?

13. Does the PLWID know what is in their plan?
    Yes   No   Unsure

14. Does the PLWID know how to use their plan?
    Yes   No   Unsure

15. Does the PLWID require support to use their plan?
    Yes   No   Unsure

16. If yes what support is received?

17. Is the support adequate?
    Yes   No   Unsure

18. If no, what additional support is required?

19. Does the PLWID know where to get help with their plan?
    Yes   No   Unsure

20. What has been the best thing about the NDIS for the PLWID?

21. Has the NDIS helped the PLWID achieve their goals?
    Yes   No   Unsure

22. If so which ones?

23. What has been the worst thing about the NDIS for the PLWID?

24. From 1 to 10, where 1 is the worst and 10 is the best, how would you rate the NDIS?

Theme 2 Accessible places, events and community

25. Does the PLWID have trouble going out to the community, events or places?
    Yes   No   Unsure

26. If yes what are the issues they are experiencing?

27. Has going out to the community, events or places changed since the NDIS?
    Got better   The same   Got worse

28. Has the NDIS helped with accessing or increasing access to the community or events?
    Yes   No   Unsure   Not Applicable

29. If no what has been the biggest challenge?

Theme 3 Decision making

30. Does the PLWID make everyday choices like what to wear, what to eat and what do to?
    Yes   No   Unsure

31. Can the PLWID change things in their if they want to?
    Yes   No   Unsure

32. If no what are the issues you are experiencing?

33. Has the NDIS helped the PLWID change things in their life if they want to?
    Yes   No   Unsure   Not Applicable

34. If no what is the main thing they want to change?

35. Is the PLWID involved in staff arrangements? (Who they are, when they come and what they do?)
    Yes   No   Unsure

Theme 4 Relationships

36. Does the PLWID know how to make friends?
    Yes   No   Unsure

37. Has the NDIS helped the PLWID meet new people?
    Yes   No   Unsure

38. If no what has been the biggest challenge?

39. Does the PLWID decide what groups you go to?
    Yes   No   Unsure

40. Has the NDIS helped the PLWID keep attending groups or join new groups?
    Yes   No   Unsure

41. If no what has been the biggest challenge?

42. Is the PLWID part of a peer network or self-advocacy group?
    Yes   No   Unsure

Theme 5 Safety

43. Do you believe the PLWID feels safe in the community?
    Yes   No   Unsure

44. If no, what do you believe makes them feel unsafe?

45. Do you believe the PLWID feels safe at home?
    Yes   No   Unsure

46. If no, what do you believe makes them feel unsafe?

Theme 6 Housing

47. Did the PLWID choose where to live?
    Yes   No   Unsure

48. Did the PLWID choose who to live with?
    Yes   No   Unsure

49. Has the NDIS helped the PLWID make changes at their home?

Yes   No   Unsure   Not Applicable

50. If no what is their main priority?

Theme 7 Employment

51. Does the PLWID work or currently looking for work?

Yes, work
Yes, volunteer
Yes, study
No, looking for work
No, not looking for work
No, retired
Unsure

52. If yes, full time, part time, casual, volunteer?

53. If yes, open or supported employment?

54. If yes, how many days do they work in a week?

1, 2, 3, 4, 5, 6, 7

55. Has the NDIS helped the PLWID access work or change things at work?

Yes   No   Unsure

56. If no, what is their main priority?

57. Can the PLWID speak up at work about problems?

Yes   No   Unsure

58. If no what stops them from speaking up?

Theme 8 Transport

59. Does the PLWID you use public transport?

Yes   No   Unsure

60. If yes what type?

Bus   Train   Tram   Taxi

61. Does the PLWID experience any problems using transport?

Yes   No   Unsure

62. If yes what are the issues experienced?

63. Has the NDIS helped the PLWID access transport or increased access to transport?

Yes   No   Unsure

64. If no what are the challenges?

Theme 9 Information

65. Can the PLWID get information about services in ways they can understand?

    Yes   No   Unsure

66. If no how can information be shared differently?

67. Has the NDIS made getting information easier for the PLWID?

    Yes   No   Unsure

68. If no what are the main challenges?

69. Does the PLWID you use Facebook?

    Yes   No   Unsure

70. If no, why not?

71. Does the PLWID use websites?

    Yes   No   Unsure

72. If no, why not?

Main priorities

73. What is your number one priority/issue in your community for PLWID?

74. What would be helpful to address these issues?