Focus group report

National Disability Data Asset

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purpleorange.org.au

Purple Orange

This paper was prepared by

JFA Purple Orange
104 Greenhill Road
Unley SA 5061 AUSTRALIA

Telephone: + 61 (8) 8373 8333
Fax: + 61 (8) 8373 8373

Email: admin@purpleorange.org.au
Website: www.purpleorange.org.au
Facebook:
www.facebook.com/jfapurpleorange

Report contributors

Tracey Wallace

Ellen Fraser-Barbour

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Preface

JFA Purple Orange is an independent, social-profit organization that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families.

Our work is characterised by co-design and co-production, and includes hosting a number of initiatives led by people living with disability.

Much of our work involves connecting people living with disability to good information and to each other. We work extensively in multi-stakeholder consultation and collaborate to develop policy and practice that helps ensure people living with disability are welcomed as valued members of the mainstream community.

Our work is informed by a model called Citizenhood.

JFA Purple Orange would like to acknowledge the following people for their role in this project:

Co-design members
Ellen Fraser-Barbour
Karen Rogers
Angus Fowler
Jala Burton
Tammy McGowan

Introduction

JFA Purple Orange were engaged by The Centre for Social Research and Methods (CSRM) at the Australian National University to run a consultation to investigate the attitudes of people living with disability about the sharing and integration of their personal data for the development of the National Disability Data Asset (NDDA).

The consultation involved a series of focus groups with people living with disability that were run throughout October 2021. These focus groups included both cohort specific groups and general groups for people living with a diverse range of disabilities. In total, there were 36 participants across seven focus groups.

JFA Purple Orange established a co-design group of people with lived experience of disability to oversee this work. The co-design group was responsible for designing the consultation process and for providing leadership around the development of this report.

While there were many issues and concerns raised around the use of data in the disability community, most participants saw the potential benefits NDDA could provide. Participants emphasised the importance of including the disability community in the design, implementation and evaluation of the NDDA and felt that this would be key to its success.

This report details the findings from the consultation.

> “The data asset should be built by and for people living with disability. We should build it, it’s our information.”

Methodology

This consultation utilised co-design, focus group and targeted recruitment approaches in order to engage people living with disability and their family members.

Co-design group

A co-design group was established at the beginning of the project to guide the consultation process. This group had representation across several disability types, including intellectual disability, physical disability, Deaf/Blind and Autism. In addition, this group represented a range of age groups from young adult to middle-aged.

This group met twice during the project. The feedback from the first meeting centered around ensuring that the consultation was designed in a way that enables people to provide meaningful input. The consultation process was shaped around the feedback provided. See **Appendix A:** *Co-design Meeting 1 – Minutes,* for details about the advice provided by the co-design group.

The purpose of the second meeting was to share the findings from the research and discuss the structure of the final report. The feedback from this meeting was used to prepare this report.

Research participants

Participants were invited to register to be involved in the focus groups via Eventbrite. Several avenues were used to recruit people for the various focus groups, including:

- A direct approach to members on the JFA Purple Orange stakeholder list. JFA Purple Orange holds a list of people that have nominated to be involved in our work.
- Participants for the intellectual disability focus group were approached through a self-advocacy organisation called Our Voice SA.

- Participants for the CALD focus group were recruited by a Community Leader in the Bhutanese community.
- Participants previously involved in JFA Purple Orange work that indicated consent to be contacted for future work were emailed.
- Young people were recruited via the Enabled Youth Disability Network.
- A direct approach to members of the Local Government Advisory Group (a group of people living with disability that have been recruited to provide advice to the Local Government Authority).
- Emails to partner orgnaisations in Victoria and NSW.

In total, there were 36 participants involved in this research. Most of the participants lived in Adelaide, with only four participants from other areas (three from regional SA and one from Victoria).

Participants represented lived experience across a range of disability types including physical disability, cognitive disability, intellectual disability, Deaf/Blind, vision impairment, acquired brain injury, autism and psychosocial disability.

Women were overrepresented in the research, with 27 participants identifying as women, nine as men and one that indicated they would prefer not to say. This is not uncommon in research in the disability space.

Furthermore, there were 10 participants that identified as being from a culturally and linguistically diverse (CALD) background. No participants identified as being from an Aboriginal and Torres Strait Islander (ATSI) background.

Focus groups

Seven targeted focus groups were run across a two-week period in October. Of these, five focus groups were run online via Teams and two were face-to-face in Adelaide. Based on advice of the co-design group, cohort specific focus groups were run for people living with intellectual disability, people living with psychosocial disability or Autism, young people and people from a CALD background.

The decision to run cohort specific groups enabled the exploration of issues that may be relevant to that particular cohort; and ensured there was representation from specific cohorts.

The details of the focus groups are as follows:

- Focus group 1: General cohort online - 7 participants.
- Focus group 2: General cohort online - 5 participants.
- Focus group 3: Psychosocial and Autism cohort online - 3 participants.
- Focus group 4: Young people living with disability (aged 18-30) - 5 participants.
- Focus group 5: General cohort online - 5 participants.
- Focus group 6: Intellectual disability cohort face-to-face - 3 participants.
- Focus group 7: CALD specific focus group face-to-face with the Bhutanese community - 8 participants.

JFA Purple Orange attempted to organize a cohort specific group for people in the ATSI community and people from NSW or VIC, however this proved to be unsuccessful in the project timeframes.

Participants were provided with some background information about the research and the NDDA prior to the focus group, including a link to the NDDA website. Further information about the research, including the purpose, was provided at the start of the focus group. Consent to participate was sought from all participants and they were reminded of their right to withdraw at any time. Participants were provided the following information in relation the confidentiality of the information they provided:

- Everything you say will be treated confidentially.
- When we write our report for the ANU, we will not identify any participants by name.

- The feedback you provide will be used by the ANU to provide a report to the NDDA and will form the basis for decision-making to improve the development of the NDDA.
- We would also just like to remind everyone that we all have a responsibility around confidentiality of today's conversations, so please respect the confidentiality of others in the group also. What's said in this focus group shouldn't be shared elsewhere.

Participants were also informed that the information they provide may end up in a report that is made public, but that they would not be identified in any way.

Discussion questions were developed to guide the conversation, however these questions were adjusted depending on the group and the direction of the conversation. The main questions that were addressed were:

- What sort of privacy issues are you worried about in relation to information that currently is collected about you?
- What do you think your data should be used for? What about anything it shouldn't be used for?
- How do you think the NDDA could benefit the disability community? (Explore any specific concerns if not already covered)
- Who do you think should be able to access the data and what for?
- Who should be able to decide how the data is used and accessed?

All focus groups participants were provided a $60 gift voucher to thank them for participating.

Ethical considerations

This project was designed in accordance with the JFA Purple Orange Ethics Protocol. All participants provided informed consent prior to taking part in the focus groups. The research team provided all participants with accessible information about how the focus groups would be conducted and provided them with background information about the NDDA prior to the focus groups. The online focus groups were recorded after obtaining consent from all participants.

All data captured during focus group sessions was stored securely in a password-protected electronic file within the JFA Purple Orange office. Data was stored in a deidentified and confidential format, with only the research team having access to the data.

Limitations

While the purpose of this research was to not to provide a full representative analysis of the views of people living with disability in Australia, it is worth noting some specific limitations in relation to the findings;

- As detailed above, focus group participants were almost all from SA. There is some risk that the attitudes of people in SA may not be consistent with those in other states. This may be particularly the casein the current environment given the COVID issues experienced and the feelings towards the government's response to these.
- The CALD focus group consisted of members from the Bhutanese community. The views put forward by this group should not be seen as representative of the entire CALD community given that there are many CALD groups and differences between groups in terms of culture and ethnicities. It is important that further work is done to explore attitudes across different communities.
- The participant numbers in the psychosocial/Autism and intellectual disability cohort specific focus groups was small. Both groups had only 3 participants. It is worth noting that some participants in other focus

groups identified as living with a psychosocial disability and intellectual disability, however it would be beneficial to explore the views of these cohorts with more participants.

- It is likely that this research underrepresents people from harder to reach communities. Given the short timeframes to undertake recruitment and focus groups, there was a reliance on connecting with people that we knew. Further work is needed to better represent specific views of people that are not well connected to advocacy agencies, including ATSI people.

Findings

This section reports the findings from the focus group. The findings have been grouped into broad themes related to the discussion questions explored. These include:

- Attitudes towards privacy of data
- What data should be used for
- Concerns about data use
- The benefits for the NDDA
- Concerns around the NDDA
- Access to the NDDA
- Oversight of the NDDA
- Cohort specific observations

It should be noted that there is some overlap between these sections. Where this is the case, the findings were presented in the most relevant section and attempts were made not to duplicate information. Cohort specific observations have also been noted where these were observed.

In general, participants were comfortable with the privacy of the data that is currently held about them, however they did detail some concerns in relation to this. Most of the privacy concerns related to identifiable information about them being shared between agencies. While some participants said they would appreciate their information being shared, such as between medical professionals, all participants indicated the importance of having choice and control over this to decide when they wanted this to happen.

Many participants highlighted the importance of ensuring that the data collected is accurate. Participants provided examples of inaccurate data currently held across government departments and felt that if this data was used to develop policies and programs, it would be misleading. Some participants also had concerns about the contextual framework in which their data was collected and the potential for the data to be interpreted differently in a different context.

Participants also highlighted the importance of having people living with disability involved in every aspect of the NDDA. This included the original planning and then oversight over who could use the data and what for. Participants described the importance of people living with disability undertaking this oversight work and developing social validation processes before the data is released to ensure the data is interpreted accurately and in meaningful ways. Related to this point, participants talked about the benefits of co-design.

> "It's our data, we should get to decide what happens with it."

Attitudes towards privacy of data

Participants were asked about what concerns they have in relation to the data currently held about them. Many participants indicated that they didn't have significant concerns about the privacy of their data and felt that data collection and use of data was inevitable.

> "Personally, I'm an open book. My experience is that I haven't had anything bad happen to me."

However, participants did indicate some concerns and worries they have in relation to the privacy of their data including:

- Some participants talked about their concerns around their data being accessed and used in the wrong way. They felt that there needs to be protections around who can access it and also a record kept of who was accessing the data and for what purposes. They felt that this would increase accountability.

> “So often the privacy of people living with disability is treated as a secondary concern.”

- Some participants had concerns about their information being accessed by organisations such as debt collectors or other services providers.
  - One participant noted concerns with hackers getting access to their data.
  - Another participant indicated that she worried about being exploited by marketing companies and her private data being used for this.
- Some participants had been caught up with the robodebt scheme which increased their concerns around the privacy of their information.
- One participant talked about her concerns with sharing information about her child. She had concerns about where the information was going and whether it would be used against her child one day. This was a particular concern due to the level of detail that was required to access special school pathways.

- One participant, who is currently employed supporting private providers, talked about concerns with data being misused and the risk that the information could become identifiable and that this could provide a "shopping list" of people that providers could approach for business purposes.

> "(if I was the provider) Guess what I'm looking for? Personal data, that's what I am looking for, and I will do whatever it takes to correlate information I am given to other demographic data to get those names."

- Some participants felt that information can be misused. They talked about governments using data to suit their own purposes. This included in punitive ways.

> "Governments worry me as they have proven themselves to be punitive. It's about the mighty buck."

- Many participants described their privacy concerns as related to information that is collected about them being misinterpreted. Participants talked about the particular vulnerability that people living with disability have when they rely on services and the "major ramifications on your life" that misused data may have. For example:
    - One participant talked about opting out of the My Health Records system as she was concerned her information about

access to drugs of dependence may be interpreted in the wrong way.

  - Another participant talked about the information she was recently required to provide to Home Affairs to support a Partner Visa. She described her nervousness about providing this (300 pages of) information and concerns about what would happen if that information was shared. "This is identified and sitting in a government department and that feels a bit dangerous to me."

> "It only takes someone to have a different understanding of information to result in damaging information being shared."
>
> "I have concerns about there being standardised ways of information being uploaded and shared and how people are taught to understand it."
>
> "It just takes one person that says 'X is independent' and then that means I get funding cut, but they are talking about my personality and not lifestyle"
>
> "I often worry about my own information being misinterpreted in some way… may impact on my life or someone else's if they don't get the full picture of the data. When you take data and take it out of context, you may get the wrong idea."

- Some participants talked about their privacy concerns when they are asked to provide information over the phone:

> “I just discovered that the telephone service from NDIS has been outsourced. I have no idea who I am talking to and no indication of what accountability they have. What if someone puts information onto the web? Who can I talk to about this?”

What should data be used for?

Participants were asked about what they thought their data should be used for and then what their data shouldn’t be used for. Participants provided many ideas around how they thought their data should be used, including to help with service provision and planning. They also provided a lot of examples of what it shouldn’t be used for, such as political gain.

> “It needs to help government; it needs to help services providers and it needs to help people living with disability and reflect what our needs are and what we think about the services that are being provided.”

Participants talked about the overarching expectation that their data and information is used in a way to benefit the disability community. Many felt that this should be the guiding principle and that people living with disability should be involved to ensure this is the case.

> “My data and information should be used to make my life better and easier...”
>
> “As long as people living with disability are involved and can have a voice, things like this can be successful.”

- Some participants talked about their data being used to streamline support and take away the hassle of sharing information. They talked about the burden of having to share their stories repeatedly to different people and that this can be very tiring, especially for people that need to conserve energy.

> “Use it in a way that takes away the stress of having to share it again.”

- However, participants also talked about the importance of having choice and control over the sharing of this identifiable information. Participants indicated that they don’t want this information shared without their consent.
- Many participants identified uses of their data relating to service provision. This included access to housing, education, employment and other support services. They talked about their data being used by researchers and policy makers to improve the services and supports for people living with disability. These services included:

  - Understanding issues around access to taxis' and other transport.
  - Providing information to inform planning for emergency response.
  - Providing information for local government to plan for accessible pathways, buildings and community organisations.
  - Supporting state and local government to drive change at a local level.
  - Providing local level information to identify gaps in service provision.
  - Supporting the mainstream community to understand what services they can provide to the community

> “Knowing where people live can give us better information on what is needed.”

- Participants talked about the ability to use data to provide information about how well funded programs are performing and to support greater funding in specific areas.

> “Make better decisions about what they are funding and what areas.”

- Many participants talked about the importance of capturing qualitative information to support the quantitative data. They indicated that the stories that support the data are just as important as the data itself. However, they noted that budget is often tied to quantitative data. One participant suggested introducing a requirement that quantitative data can't be used without some reference to qualitative data.

> "Someone needs to find a way of making qualitative data valuable to government."

- One participant indicated that data can help boost public awareness around issues and that this awareness can result in needs being met (such as changes to building codes etc).
- Some participants talked about the expectation that their data be used in a way consistent with how it was provided.

> "I would always want my data to be used for what I initially agreed to. If it is to be used in another way, I would want to be contacted for my permission."

What data shouldn't be used for

- Participants talked about the importance of the data not being used against people living with disability and indicated that it would have to be carefully managed to ensure this didn't happen.

- One participant stated that they don’t want the data to be used to make a political statement.
- Some participants cautioned against using the data to try to provide services that are thought to help all people living with disability. This doesn’t take in to account individual needs.

> “Everyone that has a disability is very different. You can’t standardise a disability.”
>
> “You don’t know enough about an individual and their needs just by looking at some data. This won’t fix things”

- Many participants talked about the importance of having people living with disability involved in making decisions about data collection and use of information . This included asking the disability community about what they think is needed.

> “We should get to choose what type of information should be used and what for.”

- Young people living with disability talked about the importance of making sure it wasn’t used in a way that could exploit people living with disability.

> “You hear about some horrifying stories about support workers taking advantage of people living with disability and getting all sorts of stuff… taking advantage of people through the access of information.”

- One participant felt that as long as each person has agreed to the use of their data, there should be no concerns with it being used. This participant provided an example about permission being given for researchers to use her genetic deidentified information to undertake research into the condition, however if this genetic information was to be used for another purpose, she would want to be contacted for permission first.
- One participant has concerns about it being used in a negative way to draw inaccurate conclusions. For example, if there were patterns such as a lot of children with autism in a particular area, we wouldn’t want this to be used to say parents in that area were doing something wrong.
- One participant had concerns that the reporting of data may lead to some changes in behaviours, such as providers wanting to “move people on” so that they don’t stay on the books of an organisation if they aren’t contributing to outcomes.
- One participant had concerns about the risks for people living with disability having a lot of information collected, stored and shared about them that was of no use. This participant felt that the information being collected was being done to cover up where the government was failing.

> “We can pretend things aren’t happening if they’re not in our dataset. Why isn’t the data reflecting it, because we don’t collect it!”

Concerns/considerations around data use

Many participants detailed concerns in relation to the data that is currently collected and felt that more work was needed before a useful NDDA could be developed. These concerns related to both the accuracy of the data and also the nature of the data collected.

- Some participants felt that data currently reported by service providers doesn’t capture what services are actually achieving. One participant noted that the data that is being provided at the moment doesn’t match up with what people living with disability would expect to be provided through to government.
- Another participant stated that current systems and data (and the people using these systems) are not well set up for the collection and dissemination of good data to inform policy of a realistic picture of what’s happening on the ground.

> “The data is just not built properly. It’s not built in a way that can provide genuine outcomes, experiences, needs for the people that the services are supposed to support.”

- Some participants felt that the outcome data currently collected and reported is set around financials and timelines, not the impact on peoples' lives. For example;
    - if you are a DES provider, you get a payment for certain milestones, which might not reflect outcomes. The milestone may be that the person has applied for 50 jobs, this is not an outcome.
    - in the advocacy sector, you just need to provide the number of people seen, rather than the actual outcomes of the work.

> "In order to implement good policy, you need good data."

- Participants in the CALD specific focus group described the language barriers they face and how this, combined with low education levels, may mean the data they report is not accurate:

> "There are people that can't even understand their own language as they are uneducated. Therefore, information about us may not be accurate."

- Many participants talked about the need to keep information up to date and accurate. They had concerns about the data being misleading if this wasn't the case. There was an example provided around inaccurate information passed on to NDIS from SA Disability and concern that this inaccurate information could end up in the data asset.

The benefits of the NDDA

Participants were asked how they thought the NDDA would benefit the disability community. Most participants were optimistic about the benefits they felt that the NDDA could provide the disability community and felt that the potential benefit of the NDDA outweighed the any concerns they had around their data.

> “Potential benefits are huge, it just needs to be managed well.”
>
> “While there may be some negatives, it will be much more useful than a negative thing.”
>
> “It can benefit the disability community in pretty much every way.”
>
> “Building a bigger and better picture of what people living with disability lives look like and their experiences.”
>
> “If the stated goal could be realised, that’s perfect, that’s exactly what we want it to do.”

Participants provided many examples of how the NDDA could be used to benefit the community, including;

- The design of services.
- Employment, including employment of people living with disability being employed to work on the data asset.

- Providing a snapshot of the employment history of people living with disability to enable a greater examination of employment situations and experiences.
- Proving information on how much it costs for someone with a disability to live their life.

“The cost of a disability isn’t really factored into things”

- Providing accurate locational information in terms of density and demographics for councils and charities.
- Determining transport needs, which is a big issue in the community.
- Providing information around what programs are working and which are not.
- Working out the needs and who to fund.

“Provision of funding could more reliably be put where it is needed”

- Providing information to make organisations accountable.
- Providing information to support research and evidence.

- To provide evidence to support arguments for advocacy.

> “If a dataset could provide an evidence base to support advocacy, that would be amazing”

- To gather information about different communities. For example, one participant talked about the lack of data around how many CALD people have a disability.

> “Less than 3% of the CALD community access the NDIS, but we don’t have any data around how many people from CALD communities actually have disability”

- Similarly, the NDDA could provide data about people with rarer conditions. Access to more data could enable policy makers to support people with less “mainstream disabilities”. Participants with rare conditions noted that sometimes these communities get left behind because there is a lack of data.
- To help build skills and capacity of the community to provide services to people from CALD backgrounds.
- To not only show what we do do, but to show where the gaps are. For example, people that have intellectual disability are often more disadvantaged, the NDDA may be able to highlight this issue.

- The data could highlight the low quality of services so this can be addressed. Furthermore, the data could be used to safeguard people. Participants reported that more understanding around the quality of services will help with this.

> “We want to use the data to change the sector.”
>
> “Use the data to help people, not to police people.”

- It could encourage others. If someone can see that another person like them has achieved something, that might make them want to try also.
- It could provide pathway information and show what people are doing.
- To support the funding of self-advocacy. Participants living with intellectual disability shared stories about how isolated some people were before learning about self-advocacy and now they have a voice and dreams and are working, moving out independently etc and the data might help to show this so there can be more services like this to help people.
- One participant talked about the large gap between what Supported Disability Accommodation (SDA) specifications say and what people actually need. The participant talked about how the NDDA could be used to demonstrate what people doing and what the alternatives are out there.

Concerns around the NDDA

In addition to the general concerns around the use of data, participants also noted specifics concerns in relation to the NDDA.

- One participant was concerned about how secure the systems would be and who would be responsible if things went wrong? This participant was concerned about a lack of redress.

> “If the government is going to do automated things, the government needs to take full responsibility when it goes wrong and provide some redress. You don’t want your data wrapped up in something… you know, you want it to be used in something that will bring about positive change.”

- Some participants raised concerns about incomplete datasets and noted that some people (or aspects of information) may not be collected as data in the system and this needs to be considered when looking at the data. An example provided by one participant was around the medical expenditure information in Medicare not being accurate. They noted that people spend a lot of money on health needs outside this.
- Many participants talked again about concerns about data being used out of context.

> “Allow us to unpack what the data is saying and what it shows.”

> "People living with disability need to be able to provide the context around the data that is collected and used. This is really important so that the data gets used in the right way."

- Another participant had concerns about the use of her data by the government and whether it would be used within a human rights framework.

> "I would feel more confident if we felt that the government had the ability to work within a human rights framework. My experience tells me that they really don't."

- Some participants talked about the need to have things explained clearly to ensure people feel comfortable and safe around the development of the NDDA.

> "It's harder for people living disability quite often to understand things, with communication and things and if they don't make us feel safe with this then none of us will want to be in it."

- Participants talked about the power of knowledge and the importance of providing accessible information to the disability community to increase confidence. One participant felt that if there was confidence with the NDDA and that it will be used to help the disability community, it will be fine.

> “If I feel intimidated in any way by something that comes up, then I won’t do it. I get scared and I have mental health issues and I just can’t do it”

- Some participants talked about the importance of ensuring that the NDDA is evaluated. There was a call for regulated and regularised evaluation by the community and other nominated oversight bodies.

Who should be able to access the NDDA data?

Participants were asked about who they thought should be able to access the data in the NDDA. There was some overlap in the responses to this question as what was covered in the section above, however some additional views provided included:

- Many participants indicated that they should have control over who should be able to access identifiable information about them.

> “The information is about me, so I should give permission around how it is used and I would like to have control over this.”

- However, many participants indicated that they were comfortable with high-level unidentifiable information being available to be used more widely.
- Furthermore, some participants felt that the data should be available to everyone in the community and should be set up in a way that it is easy for people that don't have experience with data to use it. There was a suggestion that reports could be created and accessed by more people.

> "It shouldn't be data that is hidden. In terms of what you can do with it, there should be an ethics process, in the same way they do for universities."
>
> "It could be like the Census data and could be used by lots of people."

- One participant felt that the people that access the NDDA should be a smaller group than who can currently access information about him. He talked about concerns he has with who can currently access information about him:

> "Every time I do a review, I have to tell my life story, that's at least 4 people that have my entire life story. If you start linking that up to the tax office and other departments, that will be thousands of people that know my life story."

- One participant talked about the importance of clearly defining who has access to different parts of the data.
- Participants listed people in the community that they thought should be able to access the data including policy makers, health professionals, other people with disability, disability advocacy organisations, government bodies and service providers.
- A concern raised around if who has access is in law, the government can make changes to this without consultation.

Oversight of the NDDA

Participants were asked about who they thought should get to decide who should be able to access the NDDA and for what purposes. Participants also provided input around oversight of the NDDA. The main finding related to the importance of providing people living with disability oversight and decision-making powers in relation to the NDDA. This included the development of the NDDA, decisions around who could access it and social validation of any findings. The following specific example was provided by one participant;

> “I suggest a small committee similar to a research Ethics Committee comprised of senior people with lived disability experience, at least one lawyer, and the senior government IT Privacy officers. Bound by legislation to comply with privacy laws - and United Nations conventions. Also very strict records kept of who does access the data including their reasons for it, again bound by legislation.”

- Some participants wanted to be able to decide at an individual level what their data is included in. One participant noted that they might feel confident with their data going to health professionals and policy makers, but not others.

> “If we don’t want to be part of the data asset, we should have that choice.”

- Many participants made general recommendations of a committee of skilled people living with disability having oversight over data assets and deciding where and how it can be used.
- Some participants suggested a series of committees to manage different areas of the NDDA. For example, people with understanding and skills in education should oversee education data.
- One participant suggested a disability equivalent of an ICAC on the NDIA and the NDDA “that has some teeth!” They suggested that this committee have obligations to report to advocacy organisations in addition to government:

> “They catch someone misbehaving with data, there are punitive mechanisms. There needs to be oversight of probity.”

- Many participants talked about the importance of co-design and how it should be included in the development, implementation and the evaluation of the NDDA. Participants indicated that co-design should be used at all levels – in all decisions, including into the final product and permission decisions.

> “My favourite thing in the whole world is co-design, but it needs to be done properly where there is not an imbalance of power where there is the professional or government saying ‘we’ll get the opinion of people living with disability’ but then ‘that’s it, thank you very much for your time.’ It’s got to be lived experience all the way, every step of the way, working with them, keeping them accountable so they don’t forget why they developed it in the first place.“
>
> “Nothing about us without us.”

Cohort specific observations

Participants living with intellectual disability found it difficult to understand the term “privacy”. They understood privacy to mean having physical privacy, such as people knocking before entering their room. Participants living with intellectual disability also had trouble understanding the use of the term “data” in this context. They understood data to just mean a number. The group related a lot more to the term “information”. After further conversation, some participants indicated that there was private information about them that they didn’t want other people to know, but they didn’t indicate any general concerns around data privacy.

Participants living with intellectual disability also talked about their concerns that information currently held about them wasn’t really enough information to understand their situation. They talked about how the government “should just come and talk to us” if they wanted to know information, rather than trying to get the information from other places.

More work is needed with people living with intellectual disability to ensure they are able to understand how their information is being used. The participants in the focus group provided the following advice to support people living with intellectual disability to better understand the NDDA:

- Make it simple
- Spend time with the people to help them to understand
- Visual information helps people to learn. Make sure you consider this.
- Provide Easy Read versions of all documents
- Use the term “information” rather than data
- Listen to people living with disability

The participants in the CALD specific focus group didn’t indicate specific privacy concerns about their data. They said that they trust the government to use their information properly and didn’t have concerns with the information they share. They believed that they needed to share information about themselves in order to get the support they needed. This confidence and trust was in contrast to the governments in the countries they had come from, where they felt their data was often used against them.

Many of the participants in the CALD specific focus group talked about the language barriers they face when trying to access information about services. While this was not a focus of this research, this was clearly a big issue they were facing:

> “We want to know how to access services. We don’t know where to go to get help.”

There were also some participants from a CALD background in other focus groups. Once participant spoke about her concerns about being in a minority group and that data about her may be used against her:

> “As a black disabled woman, I’m very hypervigilant about data and what is reported. This nation is known for using information about minorities against them. I don’t feel confident about data and privacy and worry a lot about this.”

She went on to say that sometimes different systems force her to report different details of her life and she worried about these systems being aligned and used against her. As a single mum with a disability, she is concerned about the way she describes her disability to the NDIS which is reliant on proving deficits and forces people to think about themselves on their worse day. She is concerned about how this could at some point be used to demonstrate she is unable to adequately care for her child.

Another participant from a CALD background described his concerns with the term “privacy.” He noted that for many people that are from a CALD background there is limited understanding of words such as ‘privacy’ and ‘consent’. He spoke about the fact that these words may not translate well into other languages:

> “The word consent isn’t something that is understood. A person may not understand what this word means. “I had to learn what this meant and what information I should let go of.”

Conclusion

The findings indicate that while most participants detailed benefits that could come from the NDDA, there are many issues around privacy and data accuracy that need to be worked through to ensure the disability community has confidence in the NDDA.

There appeared to be a correlation between people that had had negative experiences in relation to their data or service provision in general, which strengthened distrust towards the NDDA and government misuse of data. Further work is needed to understand these issues and strategies for addressing them.

Further work is also needed to explore issues within specific cohorts. For example, further exploration of issues in multiple CALD communities is needed. The issues identified by the CALD focus group highlighted the need for more consideration of language barriers and how these impact access to and provision of information.

It is important to note that almost all participants in this consultation were from SA. It may also be useful to consider a national survey to provide greater representation of the views of the disability community at a national level. The findings from this report could be used to inform the development of survey of this nature.

Many participants emphasised the importance of investigating the accuracy of the data included in the NDDA to ensure it reflects the experiences of people living with disability. This issue may require considerable work by the NDDA team, however it will be essential to success.

A key message coming through every focus group was the need to ensure people living with disability are in leadership roles in relation to the oversight work that is undertaken within the NDDA. This will not only serve to create a NDDA that is more accurate and useful, but it will also build trust and credibility in the disability community.

JFA Purple Orange would like to thank the Australian National University for the opportunity to undertake this consultation in the disability community. Please get in touch if you have any questions.

This paper was prepared by

JFA Purple Orange
104 Greenhill Road
Unley SA 5061 AUSTRALIA

Telephone: + 61 (8) 8373 8333
Fax: + 61 (8) 8373 8373

Email: admin@purpleorange.org.au
Website: www.purpleorange.org.au
Facebook:
www.facebook.com/jfapurpleorange

JFA
Purple Orange