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Our Voice SA Reaching Out Project

Research Report

Prepared for: Our Voice SA and JFA Purple Orange

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Short summary

Our Voice SA is a peer-led self-advocacy group for adults living with intellectual disability. The group wants to broaden the reach so that new people can learn about their rights and speaking up for themselves. They work with people living in the community and in closed accommodation across city and three regional areas of South Australia. In 2020, Our Voice SA received a 3-year ILC grant to deliver the Reaching Out project. This is the first research report for the project.

The research found that people with intellectual disability involved in Our Voice SA activities and groups participated more in the community because of the opportunities available to them from the project and changes in the attitudes of the people around them. People with intellectual disability gained confidence and experience to speak up for themselves, they learned about their rights and asked for things that mattered to them. People made suggestions and changes in their place of work, accommodation, relationships and taking part in community activities.

Our Voice SA uses different processes to achieve its goals. These include supporting people with intellectual disability to take on leadership roles, peer mentoring and board membership so that people have a voice and take part in the community. Our Voice SA use peer support (making friends and knowing other people with intellectual disability) across all the activities. Peer support is an effective way to build connection and self-advocacy awareness of people with intellectual disability.

There are also challenges to the Our Voice SA self-advocacy model. To successfully reach out to new people in closed systems and in regional areas depends on relationships and building trust with local organisations and accommodation providers. These partner organisations provide space and help connect to people to attend groups and activities. People with intellectual disability also require funding for self-advocacy and transport to attend peer support groups and other activities. The report identifies ways to address some of these challenges to the Our Voice SA self-advocacy model.

1 Our Voice SA Reaching Out

Our Voice SA is a peer-led self-advocacy group for adults living with intellectual disability in South Australia. The group was founded and is run by and for adults living with intellectual disability.

Our Voice SA supports its members in different ways to

- feel connected to peers and part of a group that have a voice (respected and listened to by the community)
- know their rights, grow skills and confidence to speak out about the things that matter to the person and the group
- become leaders and peer mentors; to build rights awareness among people with and without disability, by sharing stories and speaking in public.

The peer-led group has over 80 active members living with disability and associate members, like family and friends. About 20 ‘core’ members participate in regular monthly Our Voice SA meetings and board meetings.

1.1 Governance and self-advocacy

Our Voice SA is organised as an incorporated association. This means Our Voice SA can make their own decisions about how to help the community know about intellectual disability, speak up and let others, like the government, know about what people with intellectual disability want (self-advocacy). The peer-led self-advocacy group have a board that manages the group’s finances and makes decisions about how to achieve the groups goals. The main goal of Our Voice SA is to,

> […] support people with intellectual disability to participate in the community and to have the same rights as people who do not have a disability (Our Voice SA Association Rules, December 2021).

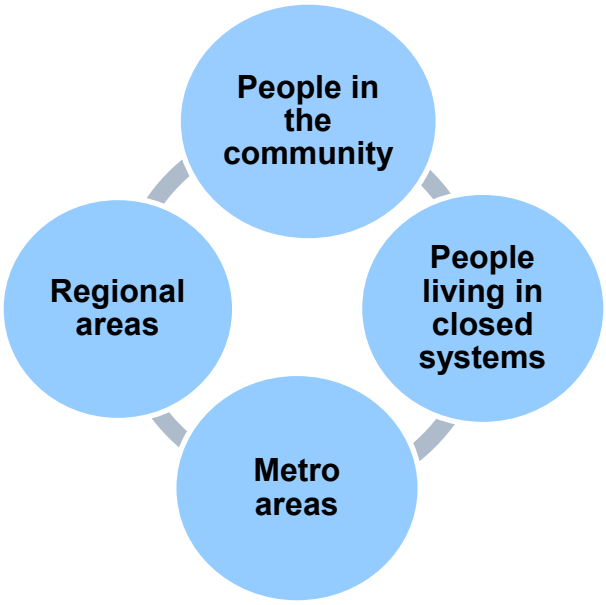
JFA Purple Orange, a non-government social profit organisation, is hosting and supporting Our Voice SA to reach out to more people with intellectual disability. Our Voice SA has two paid staff (employed through JFA Purple Orange) who support the

board in project management and deliver activities under the Our Voice SA Reaching Out project.

1.2 Our Voice SA Reaching Out project

The Our Voice SA Reaching Out project started in 2020. Under this 3-year NDIS Information, Linkages and Capacity Building funded grant, Our Voice SA wants to broaden its reach to new people about its self-advocacy work and awareness of rights. In this project, Our Voice SA works with people with intellectual disability living in the community, in closed accommodation or employment, across metro and three regional areas in South Australia (Figure 1).

Figure 1: Our Voice SA Reaching Out project groups



Part of the Our Voice SA Reaching Out project is to do research about how the project is meeting its goals, what is working well, and what can be done better in the future.

This is the first report of the Our Voice SA Reaching Out project. It was written in partnership between staff employed by Our Voice SA, researchers at Flinders University, Adelaide and the University of New South Wales, UNSW, Sydney.

1.3 Activities and processes in Our Voice SA

Our Voice SA organises and delivers activities and uses processes (Figure 2, Project Logic) to achieve the projects goals. Here we briefly discuss each of these activities delivered, and processes used in the project, before we look at what worked well, and what can be done differently in the future.

1.4 Our Voice SA activities

Peer support network meetings

Our Voice SA organise peer networks or groups in six locations. The peer support networks are held in a place of accommodation or a service, and some are held in the community, like a library. The aim of the peer support networks is to connect people with intellectual disability in a local area or within a service who may not yet be linked. Some peer support groups existed before Our Voice SA got involved; other groups were started by Our Voice SA.

Our Voice SA monthly meetings

Our Voice SA meet monthly as a group to discuss plans for the future, how the group wants to organise themselves, how to reach their stated goals (i.e., planning of the conference, co-design of workshop material), and put forward proposals and ideas to the Our Voice SA board.

Community consultations

Members of Our Voice SA are regularly invited and seek out opportunities to have a say in things that matter to them and their peers. Examples include consultations with the government, like the NDIA, the Taskforce on Restrictive Practices, and with private and state-run organisations like SA Water or the Australia National University. OVSA also held private and public sessions with the Royal Commission into the Violence and abuse of people with disability at home.

Workshops

Our Voice SA runs a series of 7 workshops with the same group of people. In the workshops people with intellectual disability can grow their knowledge, learn more about rights, learn from each other, and gain confidence and skills to make decisions, and speak out about things that matter to them.

Figure 2: Our Voice SA Reaching Out project logic

Outcomes

People with intellectual disability in urban and regional areas in the community and closed systems:

- Participate in the community
- Experience equal rights and opportunities
- Have connections, friendship and support with peers
- Have a voice and speak up
- Gain confidence, knowledge and skills to advocate for self and peers

Community and people in decision-making positions (government, services, research) value, respect and listen to advice from people with intellectual disability

Outputs

Opportunities for people with intellectual disability to participate are available

Policies and practices are inclusive, and implementation is monitored

Services, government, and allies change their expectations and practices working with and supporting people with intellectual disability

Processes

People with intellectual disability self-advocate for rights in own lives and build rights awareness with peers and the broader community through

- Leadership roles
- Board membership
- Peer mentoring
- Peer support
- Expand into regional areas and closed systems

Activities

People with intellectual disability, staff, Our Voice SA and JFA Purple Orange organise and deliver:

- Peer support network meetings
- Our Voice SA monthly meetings
- Community consultations
- Workshops
- Conference

Conference

Our Voice SA organised the second South Australian conference by and for people living with intellectual disability, it was called *Be the Boss of your Life*. The conference was held at the Hilton Hotel and attended by over 120 people with and without disability. Many of the conference presentations were by people with intellectual disability, including the interstate keynote. Service providers and organisations, like universities and vocational training services, showcased what services they offer and how they can support people with intellectual disability. A representative from the NDIA engaged with conference attendees in a session.

1.5 Our Voice SA processes

Leadership roles

Our Voice SA support people with intellectual disability to take on leadership roles, to share their stories with their peers and the broader community, and gain experience in public speaking. They do this through the different activities such as the conference, workshops and peer network groups and community consultations, also through the governance, like the Our Voice SA board.

Board membership

The Our Voice SA board consists of 5 to 14 elected members who run the group by discussing ideas and voting on options. The board make decisions about the future directions of Our Voice SA and also manage the groups' finances. Our Voice SA has two types of members: full members are people with intellectual disability and associate members can be anyone interested to support the group. After a change to the constitution in 2021, associate members, who do not have an intellectual disability, can be elected to the board and vote at meetings.

Peer mentoring

Our Voice SA have also recruited and trained three paid peer mentors. Peer mentors are people with intellectual disability who become "guides to newer people and teach them about what they want to learn and know about their disability rights" (Peer mentor in Our Voice SA). Peer mentors attend the workshops and co-facilitate the delivery of content. They can also take part in other Our Voice SA activities, like the conference or monthly meetings.

Peer support

Our Voice SA use peer support as a central part of all of their activities and governance groups. Peer support is the learning, sharing, friendships, confidence, and sense of belonging that can result from being part and knowing one's peers (people who share my experiences).

Expanding into regional areas and closed systems

Our Voice SA is using a number of strategies and activities and building relationships to reach out into services and regional areas where people with intellectual disability are not yet connected in peer-led self-advocacy groups.

In the next section of the report, we look at what the research has found about how Our Voice SA are making a difference to people with intellectual disability (the project outcomes).

2 Methods

The information for this report about Our Voice SA was collected by the staff in Our Voice SA, university researchers and peer-community researchers. The study has university ethics approval.

2.1 Co-design approach

The research team includes a community researcher with lived experience. The research methods and questions in this study were developed with people with intellectual disability.

2.2 Data sources

The data used and analysed for this report comes from four sources:

- Significant change stories
- Observation of Our Voice SA activities
- Interviews with people and staff
- Program information from Our Voice SA.

Stories of significant change

The staff and researchers collected four significant change stories. A significant change story is a written summary of a person's, organisations, or groups' experience of being part Our Voice SA and the self-advocacy work they deliver. Stories of significant change try to capture the changes that occurred over time and the factors that contributed to the success, also challenges along the way.

Observation of Our Voice SA activities

Researchers attended two Our Voice SA self-advocacy groups and events to observe how they deliver, organise, and manage the groups, how participants in the groups and activities participate and respond. Observations are then written in a short document.

Interviews with people and staff

We interviewed two people with intellectual disability and two staff members in Our Voice SA. The interviewers used inclusive techniques so that the interview questions were flexible and tailored to the person and their experiences.

Program data

The staff in Our Voice SA collect information about the self-advocacy work they deliver. The program data included numbers of people attending workshops and meetings; workshop notes and other material; videos about the work and impact of Our Voice SA; feedback surveys; written project and program documents. The staff de-identified the documents (removed people's names) and shared selected information with the researchers.

2.3 Analysis

The researchers discussed the key themes arising from the research and analysed the data using a thematic coding framework and qualitative data software (Nvivo12). The themes came from the research questions.

All the researchers contributed to writing this report.

3 Outcomes of Our Voice SA

Our Voice SA wants to reach people with intellectual disability in metro and regional areas in the community and closed systems, so that they can:

1. Participate in the community
2. Experience equal rights and opportunities
3. Have connections, friendship and support with peers
4. Have a voice and speak up
5. Gain confidence, knowledge and skills to advocate for self and peers

The outcomes of Our Voice SA come from broader changes (the project outputs), including:

- making sure that there are opportunities for people with intellectual disability to participate
- policies and practices are inclusive; and
- services, government, and allies change their expectations and practices about working with and supporting people with intellectual disability.

3.1 Participate in the community

People involved in Our Voice SA activities and groups participated in the community through the opportunities made available by Our Voice SA and changes in attitudes of people supporting them. They also gained confidence and experience to speak up. These skills had flow on effects on people's community participation.

Personal growth (I apply what I learn to my own life)

The interviews and stories of change found that active members of Our Voice SA and people taking part in the workshops and peer network groups have taken the "skills and confidence they learn" in the meetings and groups into their own life and community in a wide range of ways. Important life changes included applying for work, attending job interviews, or finding paid employment, also moving in with different people or moving out of home.

Participants in the workshops and peer network meetings reported a range of significant changes to their life, including setting boundaries in relationships (with employers, family, paid carers, housemates), making daily life choices, and speaking up when they were unsatisfied in their employment, living situation or with their relationships. Shane's story (Story of Change 1) shows the powerful impact of becoming a peer mentor, what it means to gain confidence and help break down low expectations. Peer mentorship has provided the opportunity for Shane to "do what's right for you and take the next step in your life" (Shane).

Figure 3: Story of change 1: Our voice SA peer mentor

Story of change – Our voice SA peer mentor

Shane (not his real name) has been a part of Our Voice SA for almost 3 years. He has a paid role as a Peer Mentor and a volunteer role and is a board member. Shane likes being part of Our Voice SA because "people tell their stories". He explains, "we are all allowed to put our point across" and discuss how to make things better. "The peer group support each other to be happy, safe, and do what's right for them".

Shane says that being a part of Our Voice SA has made a huge difference in his life. Before he joined, he worked in jobs where he felt less respected. Being part of Our Voice SA "gave me confidence to speak up… It gave me a voice". He says this helped him to move to a new and more exciting job that he loves. Shane is also working in systemic advocacy at state and national levels.

Shane is very busy and active in his work and private life; he has hopes and dreams for the future. He is passionate about continuing his education and wants to attend university. Shane believes in the right of people with intellectual disability to have the same rights and opportunities as people without disability. When the NDIA did not support one of his goals, he decided to appeal their decision. Shane explains that an important step in his journey was to find his voice and to have confidence to speak up. He "was learning public speaking skills".

A few years back, he joined a public speaking group so he could learn "to know what to say and how to say it." This has taught him how talk to people, anyone "even the

Premier of SA", how to put your point across and have people listen to you. This confidence to speak up also helped him to apply successfully for jobs.

3.2 Experience equal rights and opportunities

Participants in the workshops learnt about their rights and how to apply these ideas to all areas of their life, not just work life and one's immediate work environment (Story of Change 2: Supported employment: setting up an employee feedback group).

Workshop participants felt encouraged to continue to take part when they knew that their input and suggestions were shared with senior management in a safe way without their name. Some said that they started seeing changes in their work and living environment, relationships and interactions with other people as a result of changed policies, practices, and expectations towards people with disability.

Figure 4: Story of change 2. Supported employment

Story of change – Workshops in supported employment

A large supported employment service did not have a way to receive feedback and ideas from their employees. The service approached Our Voice SA to help them set up a group and develop employees' skills and knowledge about their rights and how to speak up and give feedback.

Our Voice SA met with a group of employees living with intellectual disability and found that many people did not know about how to speak up or what they could speak up about. Our Voice SA staff worked with the supported employment service to set up workshops to build employees' capacity to give feedback to the organisation and its board.

Our Voice SA ran the workshops focusing on self-advocacy, human rights and decision making across a several life areas. When the workshops began, it was difficult to draw responses from participants. When they were asked a question many people looked away or gave an answer without confidence in their own words. As the workshops progressed, participants began to understand and apply the ideas of speaking up, speaking their mind, trusting in their abilities and expertise. The Our

Voice SA facilitators found it increasingly easier to involve participants in conversations and collect critical ideas about how their employer could improve the working conditions, social and safety aspects of their working environment.

Towards the end of the workshops, people reported statements like, “I don't let anyone put me down" and "I like being able to speak up". Many of them said they had changed in the process. One person noted, "I think we have changed. I remember saying to my housemate a while ago that I would like to be confident like her and now I am."

In the feedback sessions, participants said that they really enjoyed a peer mentor coming into some of the sessions. Hearing someone speak who shared some of their experience “was powerful” and felt that “the peer mentor attending, and his ideas, helped us a lot”.

Stakeholders suggested that the involvement of Our Voice SA in community consultations (with government and advisory bodies) would lead to positive impact on the lives and rights of people with intellectual disability more widely.

3.3 Have connections, friendship and support with peers

People who took part in workshop series and peer network meetings said that “making friends, listening to peers, helping each other, and being all together” and having fun together were central parts of what they liked about the training sessions (Figure 5).

Figure 5: Feedback workshop series, Group 1

What we like about the Our Voice SA training workshop series

- We can complain about things.
- Speak up more about things.
- Have a say.
- We can help each other.
- Company and make friends.
- Interesting, fun and enjoyable.
- Listening to everyone.
- Learn new things.
- Being all together
- I tell others about these meetings.

Making connections, new friendships and building on existing relationships, learning from the stories and experiences of peers, and helping each other out, during and after Our Voice SA activities and meetings, were an important part why people wanted to continue being involved in the groups, meetings and activities.

3.4 Have a voice and speak up

Being part of Our Voice SA provided people with intellectual disability with opportunities to share experiences, life stories and ideas, to feel listened to and heard by their peers and the community.

Sense of connection in a group

In the interviews people said that there are many ways people with intellectual disability benefit from the Our Voice SA groups, monthly member meetings, and peer support networks: people can tell their stories, listen to other people, and support each other. Together, they "work as a team" and can come up with a new way of thinking. One person in the group said: "It's electrifying. It's powerful. Having a voice, all as one" (Our Voice SA member).

Sense of identity

Our Voice SA provides opportunities to share stories and experiences. Speaking up and being listened to by others, in small peer network groups or at larger events, like the conference, provided members with a stronger sense of self and identity (who I am and what I can do).

> Sharing the "stereotypes" and challenges one faces [as a person with intellectual disability], and who I am today, "makes me strong inside… It's like a beacon of light getting brighter and brighter, every time you say it. It makes me strong inside". (Conference presenter).

3.5 Gain confidence, knowledge, skills to advocate for self and peers

Our Voice SA undertake regular evaluation of the workshops they deliver. They administer a survey known as the Personal Growth Initiative Scale (PGIS) to

measure how participants feel about making decisions, speaking out, achieving goals and changing things in their life.

Being involved in Our Voice SA workshops provided participants with opportunities and resources, supported skill development and personal growth and increased confidence. The analysis of 32 pre-workshop and 22 post-workshop responses found that participants gained in confidence to speak up for themselves; 59.1% said they strongly agreed (post-workshop) up from 28.1% (pre-workshop) (Figure 6). Participants were also more confident about knowing what to do to reach their goals (Figure 7). For all findings from the Personal Growth Initiative Scale please refer to the Appendix at the end of the report (page 39).

Figure 6: I can speak up for myself, Personal Growth Initiative Scale

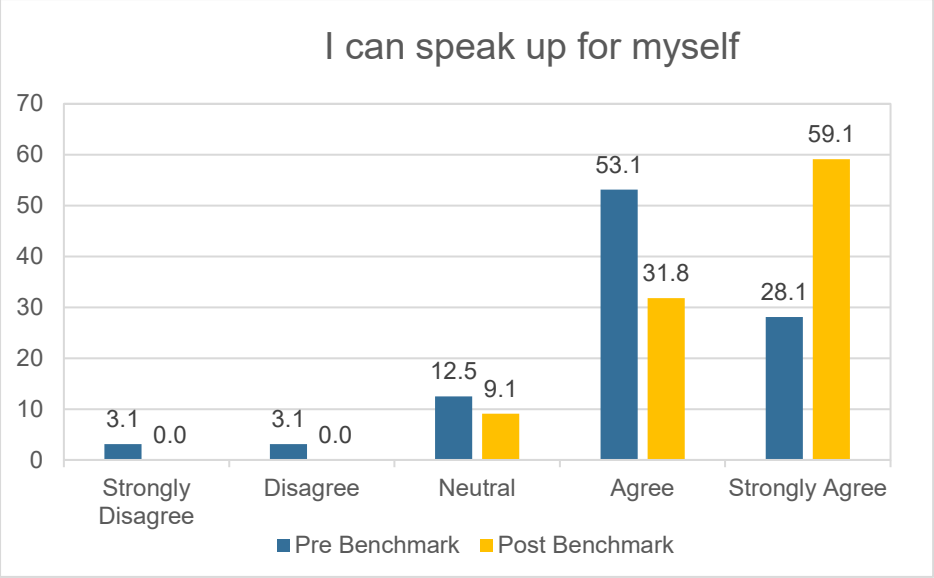
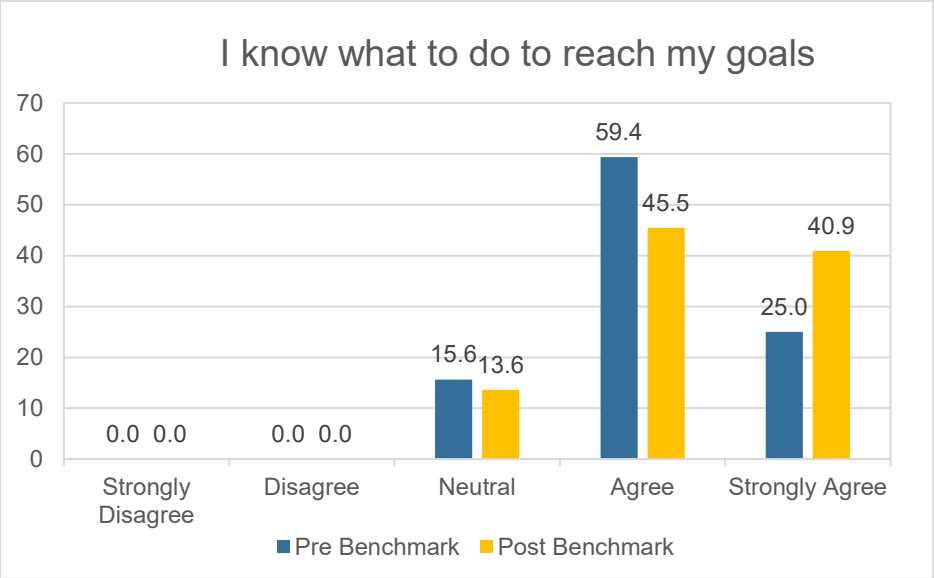


Figure 7: I know what to do to reach my goals, PGIS



Confidence, skills and speaking in public

Core members of Our Voice SA had a strong sense of the impact of their work from the opportunities to take part in consultations and advisory groups, speaking at the conference, or taking leadership and speaking up in the workshop groups. They had pride in what they do and who they are.

Feeling recognised and respected in the broader community

The group is recognised as having authority and a voice to speak on behalf of a wider community of people with intellectual disability. Our Voice SA have been invited to participate in diverse consultations for government, including NDIS policy reviews, the 2021 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, for private sector companies and university research (Appendix A). The growing number of consultations has meant that members involved in the core group feel respected as a group, one member said, “everybody knows who we are” (Our Voice SA member).

Time and involvement

Members felt more confident and more knowledgeable over time, having expertise and authority to speak up.

Over time, Our Voice SA members appear to have become more knowledgeable and confident about what it means to speak up and apply changes to their lives, and to advocate for the rights of people with intellectual disability in the community more broadly. Our Voice SA has a greater impact on members who have been part of the group and activities for longer or have been more strongly involved in the core group. They attend monthly meetings and take on central leadership roles in the project. The repeated engagement of a core group of members helps people to develop complex ideas and take initiative. One example of this is that a longstanding Our Voice SA member took the initiative to seek out funding for the conference.

4 What activities work, what are the challenges

4.1 Peer support networks

People with intellectual disability take part in peer support networks to meet their peers who live in the same accommodation, service or local area. The OVSA board come together from a broader metro area. Together they speak up about things that matter to them in their life, learn and share ideas about their place(s) of work, accommodation, and local community, see Story of Change 3 from a peer support network.

Figure 8: Story of change 3. Impact of peer support networks

Story of change 3 – Speaking up and seeing a difference

Charlotte (name is changed) is a confident member of the group. At first Charlotte was hesitant about whether anything would change by speaking up in the group organised in an employment service. As time went on the facilitators from Our Voice SA explained that after each meeting a summary of the workshop would be sent to the Executive and the Board of the employment provider.

Soon after the meetings began, Charlotte and the other members of the group started to see things changing where they work. This gave the members the confidence to speak up even more. Charlotte said,

“We love this group – we are making a difference; we are being listened to – things are changing, and we have done that for everyone at [employment provider] by speaking up.” “We are now being told when things are happening, and Management are asking for our advice.” Following a workshop about “What means home to you”, Charlotte said: “I have learnt today what home means to me and our group: Home is where I am loved.”

Charlotte and the other members in the peer group said that they were keen for the broader community to learn and “to understand more about what it is like to have a disability”. She said that educating the community, “especially children”, about disability was important because people with and without disability need to live together and need to make the changes. Charlotte volunteered to speak in person to the employment provider Board representing her Peer Support Network group and their voices.

The small group process appears to be very effective for working and engaging people living with intellectual disability, to build capacity and skills in members to advocate and speak out for themselves.

New peer support groups are organised around morning or afternoon tea. New groups have meetings 3 weeks in a row, then once a month. Regular meetings at the start allow people to build connection to the group gradually. Our Voice SA supports some of groups Our Voice SA that were formed before their support, but the groups had not met regularly without support.

Meeting face to face, in familiar and at an easily accessible place, and providing refreshments were aspects that helped with the success of the peer support network meetings.

Challenges and limitations

It remains difficult to engage new people to new peer support networks. The steps are to reach out, find people who are interested, and ensure people have the support they need to attend. These difficulties are particularly hard in regions where Our Voice SA is not yet well known in the community and services.

Organisations that are less supportive of the concepts and values promoted by Our Voice SA or have not yet worked with a self-advocacy group, can function as gate-keepers, constraining or rejecting engagement. Tensions can also arise where the preferences of peer network participants (e.g., more frequent meetings) are not supported by the organisation hosting the capacity building activities.

Lessons and future adaptation

Our Voice SA is testing new ways to reach out in regional areas. For example, instead of using words like peer network or workshop, they are offering “Coffee and a Chat” meetings. This is a more informal way of gaining people’s interest and building trust and the first connections. Our Voice SA are also piloting other ways to connect in regional areas, for example, through country connectors employed by JFA Purple Orange (the auspicing organisation for Our Voice SA) to promote the workshops/network meetings in regional areas and with local services.

Building trust and relationships with local services and organisations that are less familiar with autonomy and self-advocacy of people with intellectual disability takes time and persistence. Earning trust and respect with some organisations over time through shared activities aligned with the organisations' programs is a strategic approach.

4.2 Our Voice SA monthly meetings

Our Voice SA meet on a regular, monthly basis. The meetings are important to sustain a sense of connection to the group and keep members informed about on-going and planned activities, co-design activities, discuss opportunities for future funding applications, plan new activities to reach out and educate the broader community about the rights of people with intellectual disability.

The groups are held in person, at a location in Unley. Many members have support and funding to attend the meetings. This can include contact with a trusted and friendly taxi driver, who picks up and collects the person at the end of each meeting. Having funding available to attend meetings, including to pay for transport, and being supported by the accommodation provider, paid support worker, or a family member are important factors that make it easier for people to attend. People with intellectual disability may need reminders that the meeting is on, assistance with transport and support during the meeting.

Challenges and limitations

Our Voice SA project workers said that some regular members experience barriers to taking part in the monthly meetings. This is mostly due to their supporters and allies making decisions on behalf of the person (not to attend), or not seeing the value of the groups and meetings, and self-advocacy work they are involved in.

Lessons and future adaptation

Raising awareness about the rights of people with intellectual disability and changing expectations among services, government, families and allies of people with disability remains an on-going task for governments, families and self-advocacy bodies like Our Voice SA.

4.3 Community consultations

From 2020 to 2021, Our Voice SA engaged in over 16 community consultations (see Appendix A). The advice was to educate the community about the rights and preferences of people with intellectual disability and make clear how regulations and rules can negatively affect people living with disability and how they can be changed.

The community consultation part of the project works well. Many Our Voice SA members enjoy speaking up and advocating on behalf of their group and peers. Members are keen to attend government, public and private consultations and to take up advisory roles. People with less experience are inspired and learn from other group members.

Staff employed by Our Voice SA play an important role in this activity. They identify opportunities for the group to be involved in public debates, events and board meetings. It appeared that the government and community recognise the role and authority that Our Voice SA have, as one of two self-advocacy groups for people with intellectual disability in South Australia.

Challenges and limitations

A strong growth in individual confidence and the profile of the group meant that the members appear to be unwilling to reject the increasing number of requests to take part in research or consultations and hearings. Taking part in many consultations can be demanding on the people involved and project resources. Currently the project was managing this tension by adding shorter consultations to the end of scheduled meetings, where this was possible. This strategy may not be sufficient in the long term.

Lessons and future adaptation

The Our Voice SA board could consider developing a way to prioritise consultations depending on how closely they are aligned with the objectives of the group, so as to avoid overloading the group and its members with accepting too many invitations for consultation.

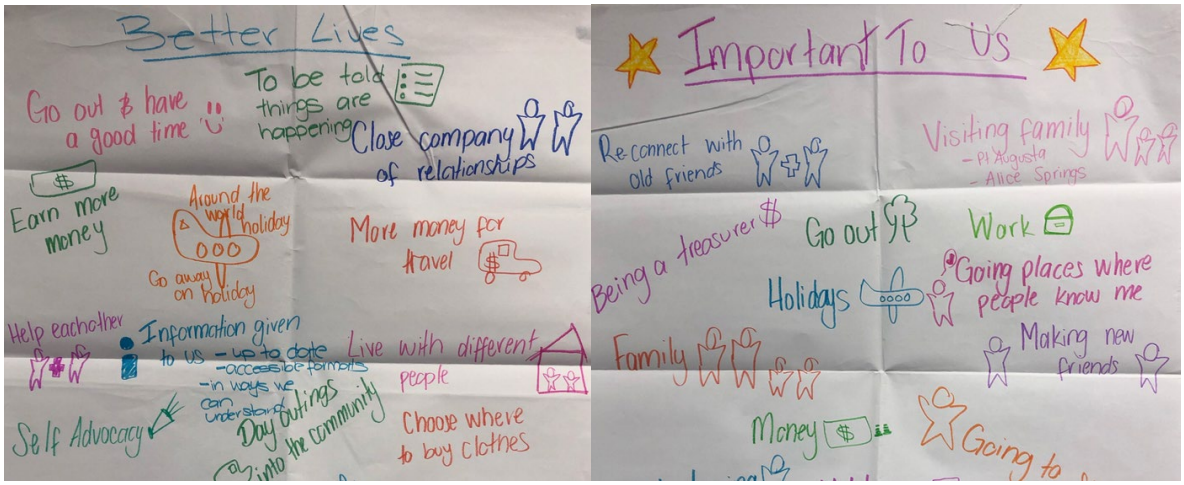
4.4 Workshops

The workshops, a series of at least 7 successive meetings, are specifically designed to learn about rights and how to speak up and make decisions about things that matter to the person in all areas of their life.

The workshop content for all workshops was co-produced with people with intellectual disability, which ensures that the content is relevant to the self-advocacy needs of participants in the workshops. Peer mentors also co-facilitate the delivery of parts of the workshop sessions (Section 3.5). For example, lived-experience stories of learning about rights and applying them to their own life, makes the workshop content more relevant to workshop participants. Involving presenters with lived experience also makes it easier for participants to ask questions and share their reflections and own stories.

The other staff who deliver the workshops and peer networks are experienced in engaging diverse audiences. They use techniques such as scaffolding and repetition in the delivery, visual material (including videos and take home booklets), providing take home material (resources and planning documents) to assist participants to make best use of the training after the workshop. They use engaging training delivery skills, for example, summarising content, using images, colours and pictures to highlight messages. They represent the discussions in visible, accessible and large formats.

Figure 9: Our Voice SA workshop material provider 2A



Staff in Our Voice SA are trained in disability related fields and university graduates in developmental education. These skills and expertise in training delivery for people with diverse abilities have helped to deliver complex topics like relationships, rights and respect, values and setting individual and group goals. The experience and skill of the staff facilitate the participation in the groups.

Staff in the interviews said that working with small groups of 6-10 people in workshops, and 4-6 people in discussions about sensitive topics, was effective. They said these small group formats allowed participants to feel heard, listened to and respected and their contributions acknowledged.

Challenges and limitations

Gaining interest from people to attend the workshops remains challenging, similar to peer network meetings. People may not always understand the relevance of learning about human rights, decision making, and self-advocacy and how these apply to their own lives.

Other barriers are structural. Some people with intellectual disability do not have the funded support and transport to attend groups; people may not find out about the events in time because they are not connected to the media used for advertising and some services and organisation or supporters do not pass on the information to them.

In addition, the challenges and fears about Covid-19 and restrictions on face to face meetings have disrupted Our Voice SA workshops. After the health restrictions were lifted in 2021, people, families and communities remained hesitant to participate in in-person meetings and workshops.

Lessons and future adaptation

Generating interest for workshops probably needs to build from the connections from other activities, including the peer support networks and the conference. Communication is usually most effective from word of mouth and personal connections within Our Voice SA and other parts of JFA Purple Orange as well as other advocacy organisations.

Online events have not been as successful for Our Voice SA workshops. Sharing successful ways of engaging people with intellectual disability in online activities from other advocacy organisations may be a way to overcome this accessibility barrier.

As peer mentors build confidence and experience, opportunities for them to increase the amount of workshop content they deliver and be actively involved in discussions with participants about workshop topics can be explored.

4.5 Conference

The Conference, Be the Boss of Your Life, the second conference organised by Our Voice SA was well attended. The number of participants with disability remained similar in 2021, where there was a heightened risk of Covid-19, with 54 participants attending compared to 62 in 2019 (see Table 1). The conference was widely publicised, attendees who had not been to many Our Voice SA activities or to the first conference took part in this event. The increased attendance was seen as a great achievement.

Table 1: People attending Be the Boss of Your Life Conference, 2021

Our Voice SA	Number of people (attendees)
Person with intellectual disability	54
Support person	33
Guests	15
Volunteers, evaluators	14
Our Voice SA and Purple Orange staff	7
Total number of conference attendees	123

The event was welcoming and inclusive. The pace of the conference was not rushed, with a relaxed schedule enabling time for attendees, speakers, presenters and supporters to physically be where they needed to be. Accessibility was available in many ways, including easy read programs and presentations, sensory rooms, ramps and pictorial menu.

The conference demonstrated leadership by people with intellectual disability and was regarded as a success by all stakeholders. People with intellectual disability, their interests and leadership were at the centre of the conference. Our Voice SA

members with disability contributed to the organisation and helped to facilitate at the conference. They held keynote presentations, primary presentations and managed aspects, including performing duties as the MC. The planning of the conference offered developmental opportunities for members, people with intellectual disability were involved in the organising committees and decision-making processes.

The conference enabled Our Voice SA members to share their individual and group successes and develop a greater sense of pride as a person and as a group.

Challenges and limitations

The conference was a well-attended event by people with and without disability. Because many people attended, not everyone had the opportunity to speak about their ideas to a larger group of people. Also, many people missed out on the opportunity to reflect on the learnings arising from the presentations together with other peers.

Lessons and future adaptation

Future conferences could make more use of the small group tables for feedback and reflection opportunities. For example, a future conference could invite a NDIA representative to speak, and the small group tables to reflect and write down questions. Subsequently the organisers could pass the feedback onto the NDIA or record the feedback on the day by going around tables and recording feedback to pass on.

A couple of people said they had come to make new friends. The next conference could consider innovative ways to create more informal socialising activities, where people from different small tables are encouraged to speak to and get to know participants at the conference.

5 Effective processes

5.1 Leadership roles

Taking on leadership roles in Our Voice SA included: being part of the decision making and voting process at board (and monthly) meetings, taking part in committees and discussions about the conference planning, preparing speeches for the conference and other events, making recordings and videos about Our Voice SA, supporting newer members to understand how rights could apply to their life, co-presenting at workshops, taking part in government, private sector and university research and other consultations.

Members of the Our Voice SA core group (including board members, active members in the monthly meetings, peer mentors) valued the leadership opportunities opened up by the project, its governance and self-advocacy activities. Participants in the workshops also took up leadership roles, for example, speaking and presenting to the board of their accommodation service on behalf of their group.

The wide range of leadership roles and opportunities offered through and enabled Our Voice SA (governance) and as part of their activities and processes (consultations, mentoring, public speaking, being known in the community) allowed members, over time, to develop new ideas and a greater sense of authority. People with intellectual disability taking on leadership roles understood that they have something important to say and people will listen to their ideas.

5.2 Board membership

Our Voice SA is managed and governed by the decisions taken by its board. The board members hold a range of responsibilities and roles, including managing the groups' finances.

Over the last 2 years the Our Voice SA project has reviewed and revised the Our Voice SA constitution. The updated constitution was developed with input from the board, a legal consultant, and facilitated by the Our Voice SA staff. The review of the constitution took significant time. Time was a critical factor to ensure that every member was heard and had input into the amendment of the constitution.

The constitution is now available as an easy read version that is approved by all board members. It confirms that full members to the group have to identify as having an intellectual disability (removing other forms of disability, autism and learning disabilities). Through the process the Our Voice SA board has received more clarity of their roles, responsibilities and accountability.

A change in the constitution is that the Our Voice SA people without intellectual disability, known as associate members, can now be voted onto the board. Once an associate member is voted onto the board, they become voting rights to vote at board meetings.

Challenges and limitations

The current governance structure of Our Voice SA broadens participation for the future. This change opens up opportunities and risks to the self-determination of people with intellectual disability.

The majority of Our Voice SA core members are older adults, some who formerly lived in the now closed large institutions. There is a generational gap to younger people with intellectual disability. To ensure the sustainability of the self-advocacy group, in the longer term, the group could look into ways of how to address the generational divide and attract younger members into the core governance groups of Our Voice SA.

Lessons and future adaptation

The evaluation offers an opportunity to consider the effect of changes on the constitution on the authority of people with intellectual disability in governance, opportunities to join the board and contribute to the board in the future, relative to board members without intellectual disability.

5.3 Peer mentorship

Our Voice SA engages three paid peer mentors. The role of the peer mentors is to become leaders and support the delivery of the workshops and other project activities. One peer mentor explained their role as, “to guide [newer people] on the way to find out about making decisions, about education, housing or safety, things in the world”, anything that the person is interested in.

Peer mentors viewed becoming a paid mentor in Our Voice SA a valued opportunity and responsibility, a way to build new relationships, refine skills and keep learning.

> Everyone has a different journey…you keep learning by asking questions… It was a huge, big positive step for me to become a peer mentor. (Our Voice SA Peer mentor).

Following a recruitment advertisement, peer mentors were interviewed, and selected for paid positions in Our Voice SA. Paid employment and training recognises the value of their contributions and role.

Participants in workshops commented that having a peer mentor present, and explain aspects of the workshop content, added value and enriched the workshops. It helped participants see the meaning of some of the workshop content and how it related to their own life.

Challenges and limitations

Peer mentors appear to have a supportive or assistant role in the workshop delivery. As their roles continue to develop over the life of the project, opportunities to extend their contributions can be explored.

Lessons and future adaptation

In the future, the project could explore how to continue to build the capacity of peer mentors and create opportunities for them to take on leadership and larger components of the workshop delivery.

The project needs to remain attentive to the needs and changing expectations of the peer mentors. This could be done by creating ways that peer mentors can provide

feedback about their experiences, their development goals, in a safe manner, without feeling they are compromising their relationships with their employer.

5.4 Peer support

Peer support is the connection and sense of belonging, learning, sharing, friendships and confidence that can result from being part of a group and knowing one's peers (people who share my experiences). Our Voice SA use peer support as a central part of all of their activities and governance groups and processes.

Across the different activities, Our Voice SA monthly meetings, workshops and peer support networks, it was evident that feeling 'strong in numbers', sharing experiences and stories, and learning and personal growth through the experiences of peers, was a powerful mechanism. For many participants in the workshops and peer network meetings, monthly Our Voice SA meetings the support and friendships with peers helped to build their sense of connection and belonging to a group and individual growth.

Challenges and limitations

While people with intellectual disability in Our Voice SA benefited from being connected to peers, learning, sharing and making friends there is a risk that the continuation of these relationships also depends on the continuation of the groups where people can meet and connect. Currently, the organisation and management of the peer support network meetings and other groups/meetings rely on government funding and paid support.

Lessons and future adaptation

Similar to the suggestions under 5.3. the project could explore how to continue to build the capacity of peer mentors and other leaders, and create opportunities for them to take on leadership roles in organising peer groups in the future.

5.5 Expanding into regional areas and closed systems

Our Voice SA is taking activities (peer network meetings and workshops) into closed systems (like group accommodation) and big organisations with existing self-

advocacy groups, also into regional areas. This is a positive and relevant development. The numbers of workshops, peer support network and other meetings in 2021, and participant numbers in each, are listed in Appendix A.

This expansion is still in its early stages. It is too early to say what the full impact of Reaching Out will be on people with intellectual disability living in regional areas and in closed systems who were not part of the original Our Voice SA membership.

Emerging feedback from the new peer networks and the organisations and services involved in the capacity building work was positive. Important to the success of the groups and meetings was to have “someone independent”, like the Our Voice SA facilitators and peer mentors come into the organisations to work with a group of people with disability. Organisations and new members said that the independent facilitation created a “safe space” to speak up about things that matter to people, especially things that were sensitive to speak about.

5.6 Cultural diversity and Aboriginal and Torres Strait Islander People

Members from cultural and Aboriginal backgrounds are underrepresented in Our Voice SA. There are currently clear no plans or strategies to engage and reach into these communities. This is something the project could explore into the future.

6 Lessons for self-advocacy

6.1 Strengths of the OVSA model

The Our Voice SA model aims to build self-advocacy, rights awareness and connection offers different levels of engagement. People with intellectual disability can take part in a wide range of activities and leadership responsibilities and roles.

This model of self-advocacy allows new and existing members, who have a strong interest or develop confidence and interest over time to participate and connect with other parts of Our Voice SA. Examples of this cross-over occurred when new participants in the peer network and workshops attended the conference.

The Reaching Out project has provided resources for Our Voice SA to expand its reach and activities, engage in more community consultations, and become known and respected in the broader community. The growth of the groups has also translated into individual growth of members' confidence and skills. They are making changes in their own lives.

The Reaching Out project has allowed Our Voice SA to hire dedicated experienced staff to co-design and develop the workshop material, deliver capacity and skills building activities with peer mentors, engage with large services and closed systems, revisit the groups' constitution and build leadership capacity, undertake project management for Our Voice SA.

6.2 Challenges to the OVSA model

Some challenges affect the Our Voice SA model and its capacity to reach out to new participants and to continue to develop the achievements of the core members.

Reaching out

Repeating workshops and peer networks in big organisations allowed people to grow their sense of connectedness and learning over time. The lessons and ideas from the peer network groups are not always easily put into practice outside the group (or in other parts of the organisation), especially where there are no processes and culture supporting principles for self-advocacy and rights.

Parts of Our Voice SA are reliant on host organisations and services (in closed systems) to provide space and assist in the recruitment of participants. Host organisations need to embed self-advocacy in the organisations policies, management and work culture. Some organisations function as gate-keepers and winning trust and interest in rights awareness is difficult as it requires a culture change for some.

People with intellectual disability rely on support, transport and funding for 1:1 support and capacity development in their support plan to attend Our Voice SA activities. Not all new members and potentially interested people have these resources allocated or are aware they can add them to their NDIS plan.

The small group processes are effective, but they are resource intensive, and it takes a long time and regular contact to gain trust and establish relationships with people, services and communities. Questions remain about how sustainable the current approach is for a wider group of people.

Governance and sustainability of the group

Succession planning, how to engage and retain younger members in Our Voice SA remains, remains important for the long-term sustainability of the group. Our Voice SA could think of strategies to engage and support younger members to step into more leadership roles in the group.

Our Voice SA is currently hosted by JFA Purple Orange. The group receive support from their host organisation but do not have a “permanent home” at JFA Purple Orange. The Our Voice SA model currently relies on receiving government funding to fund and continue its activities, groups, skills and connection building.

The Our Voice SA team and board could consider ways how to “manage forward” in closed systems and in regions where the groups are not yet fully embedded. Managing forward includes partnering with local organisations that have some interest to continue the groups, for example, because they are considering to apply for another NDIS grant.

6.3 Future directions

Relationship with closed systems

The approach of the project to reach in to closed systems and use other methods in parallel to develop community-based peer networks is a strong model.

Where peer support networks and workshops are reliant on disability service organisations to invite Our Voice SA or other peer support organisations in to develop and facilitate a group, there is a level of dependence on the provider.

In the next stage, Our Voice SA might consider how to blend the approaches, and invite people from the closed networks into the community-based peer networks. This would provide community connection for people with few social networks and could reduce their reliance on providers for access to advice and support about rights.

Longer term, Our Voice SA could seek funding to continue peer network development in closed systems based on the success of this project. Such a project may consider:

- How to develop self-sustaining networks over time
- Developing a rounded framework of rights-based action and connection-building
- Providing opportunities for feedback to services, but not making this the entire focus of the groups, so that services see the benefits of the self-advocacy work for their entire organisation
- Including expectations on service management to report to peer networks about how they have acted on issues raised.

Building on the success of the project

Our Voice SA might want to consider promoting the leadership of people with intellectual disability as speakers in other events in South Australia and nationally based on the success of the presentations at the conference. Our Voice SA could

also consider trialling a fee for some consultation work/projects. The payments could be used to build savings that could be used to fund future capacity building work/activities and assist the group in becoming partly sustainable in the longer term.

Our Voice SA could explore which parts of the model can be organised differently and more sustainably in the long-term. One area that could be expanded is to continue investing and building capacity of peer mentors to become full co-facilitators in workshop or take on other leadership roles in the project.

Driving innovation with other peer advocacy groups

Our Voice SA tried to include more technology to reach people and delivery meetings and workshops during Covid-19 and in regional areas, this approach has not been well received by many Our Voice SA members. Many older people with intellectual disability do not have the resources, support, knowledge and skills to use technology, like attending zoom meetings. A peer mentor in the interview said that "using technology can be challenging and difficult" but there "are opportunities to explore this further".

Our Voice SA could support members to learn how to access and use technology that is already available (scanners and software to read information to you), recording voice messages and sending them, or recording of videos as a format to communicate with peers and other relationships. Also, how to seek out information on the internet and social media.

The project could partner with other peer advocacy groups in Australia to find out how they use technology. Together with other groups, Our Voice SA could identify what supports are already available for people with intellectual disability and identify gaps. Based on these shared learnings they may see an opportunity to propose a research project to drive innovation and change in this space.

Relationships and collaboration with regional and culturally diverse services

The project is trialling new ways to establish pathways and connection into regional areas. Our Voice SA could continue its work by building partnerships with regional services or culturally trusted groups, develop their capacity to support and promote

self-advocacy among their community. This partnership approach could assist Our Voice SA to develop sustainable networks and connections for people with intellectual disability in the regions and with culturally diverse communities.

Appendix A: Our Voice SA in numbers

Project Data* for 2021

2021 Peer Support Networks	No. of meetings	People attending
Our Voice SA	8	64
Provider 1	9	45
Provider 2	6	47
Region 1	10	29
Region 2	9	12
Region 3	1	13

2021 Our Voice SA Board Meetings		
	10	40

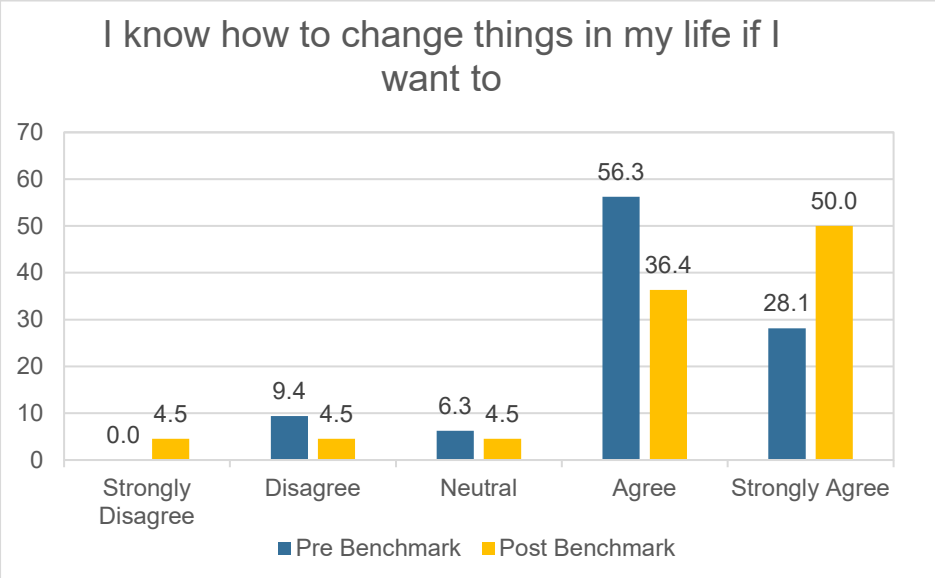
2021 Capacity Building Workshops		
Provider 1	7	34
Region 3A	9	60
Region 3B	9	60
Provider 2A	8	22
Provider 2B	8	45

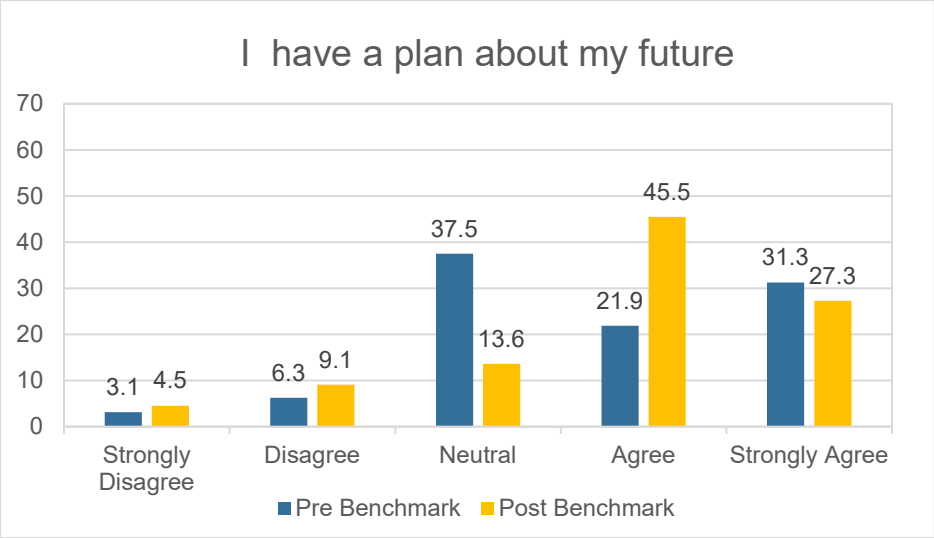
2021 Consultations		
NDIS		11
Restrictive Practices		4
PO Strategic Planning		5
SA government		4
DRC		1
University advisory 1		4
University advisory 2		4
Business consultancy		3
DRC		2
IDPWD 2021		3

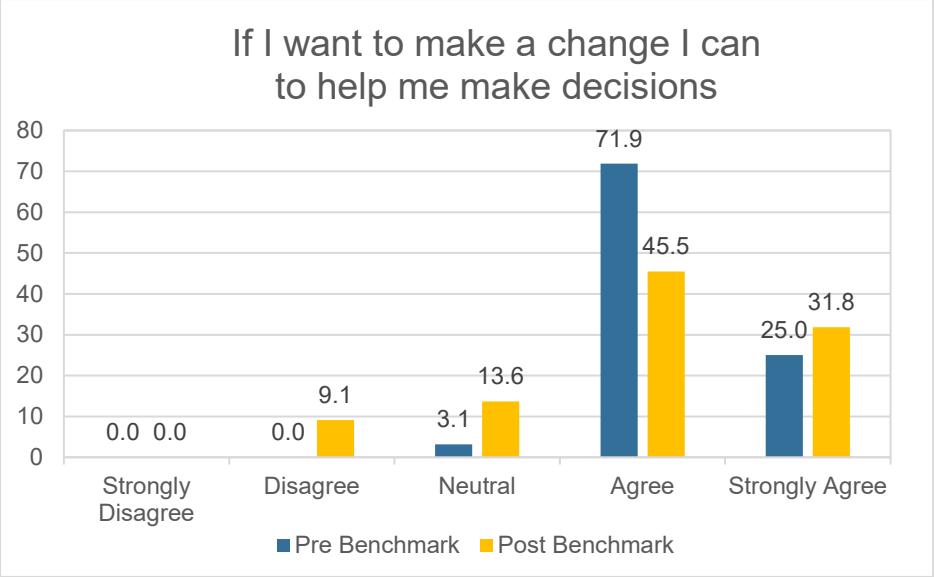
2020 Consultations		
Co-design	3	7
Taskforce		5
IDPWD 2020		4
DRC		9

*Anonymised for confidentiality

Personal Growth Initiative Scale, 32 (n) pre-workshop and 22 (n) post-workshop






If I want to make a change I can to help me make decisions
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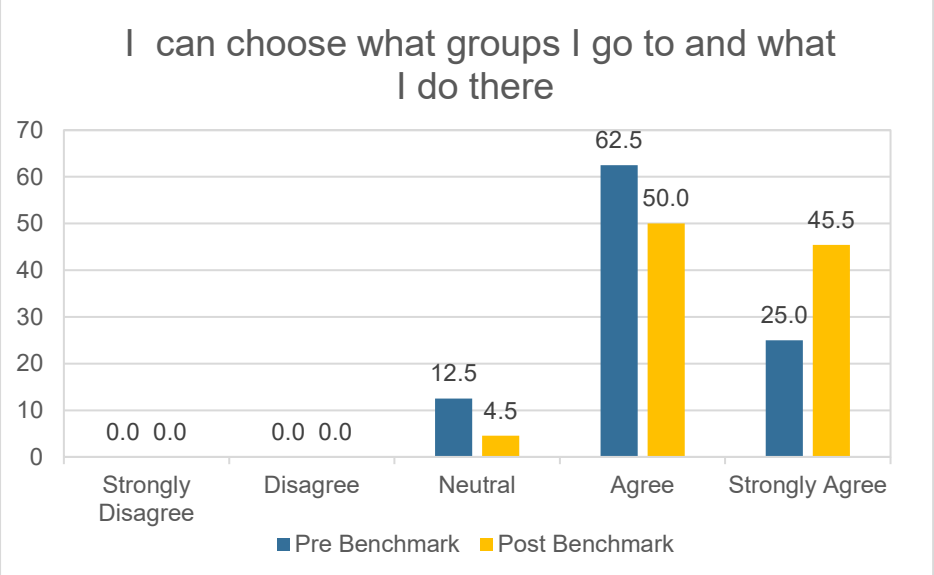
70
60
50
40
30
20
10
0
0.0 0.0
0.0
9.1
3.1
13.6
71.9
45.5
25.0
31.8
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre Benchmark
Post Benchmark


I can choose what groups I go to and what I do there
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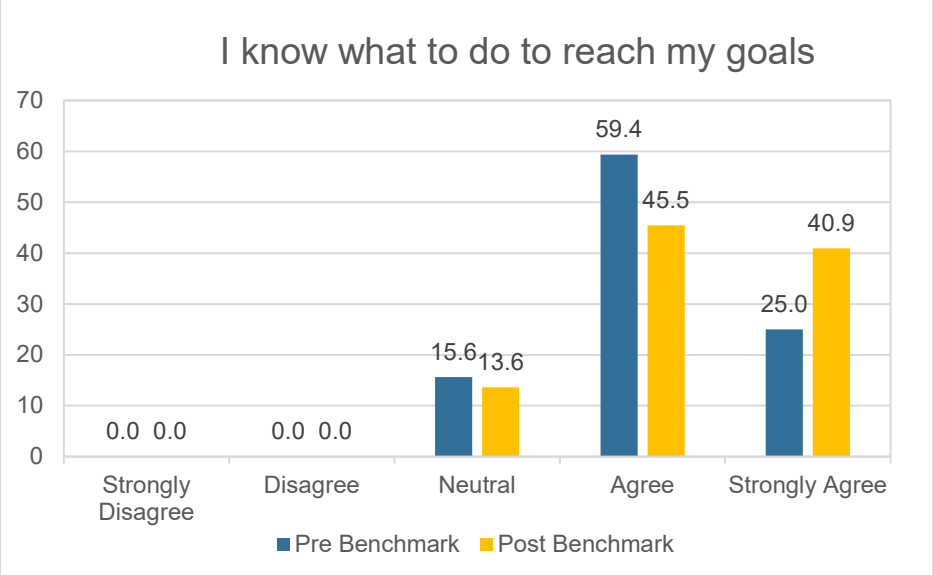
60
50
40
30
20
10
0
0.0 0.0
0.0 0.0
12.5
4.5
62.5
50.0
25.0
45.5
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre Benchmark
Post Benchmark


I know what to do to reach my goals
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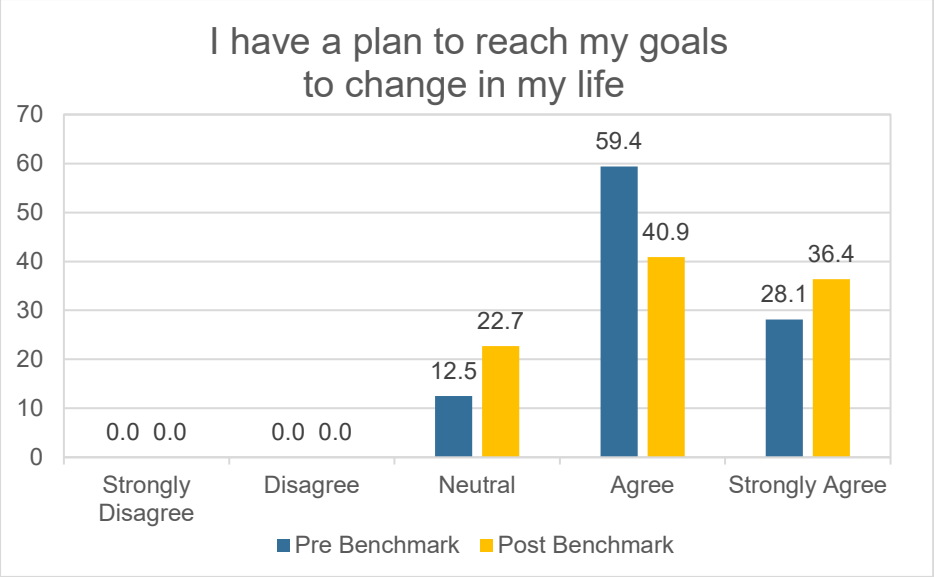
60
50
40
30
20
10
0
0.0 0.0
0.0 0.0
15.6
13.6
59.4
45.5
25.0
40.9
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre Benchmark
Post Benchmark


I have a plan to reach my goals to change in my life
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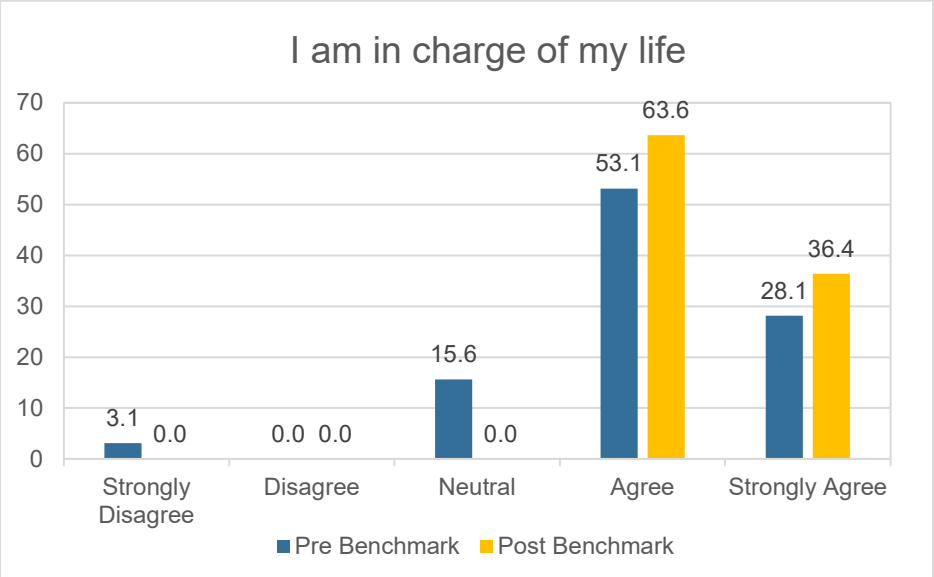
60
50
40
30
20
10
0
0.0 0.0
0.0 0.0
12.5
22.7
59.4
40.9
28.1
36.4
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre Benchmark
Post Benchmark


I am in charge of my life
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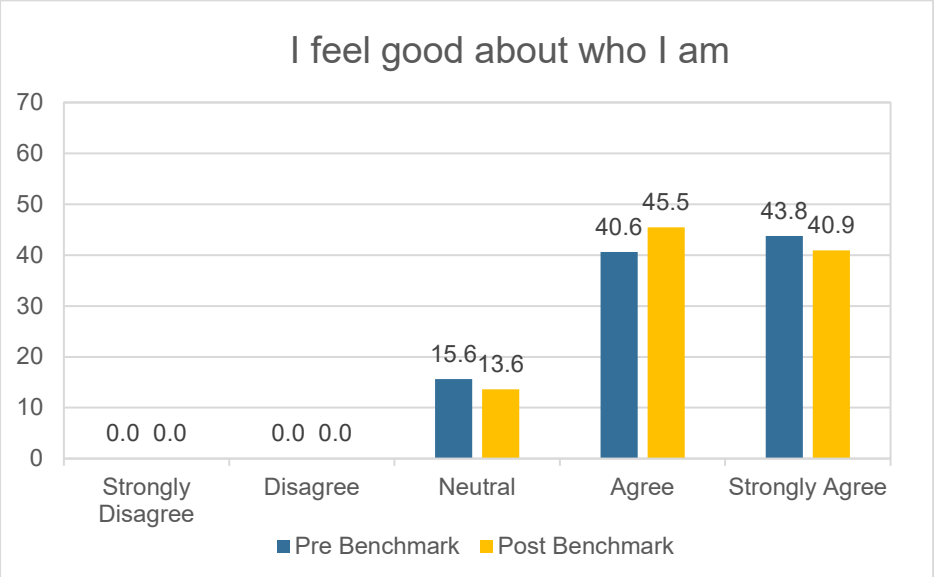
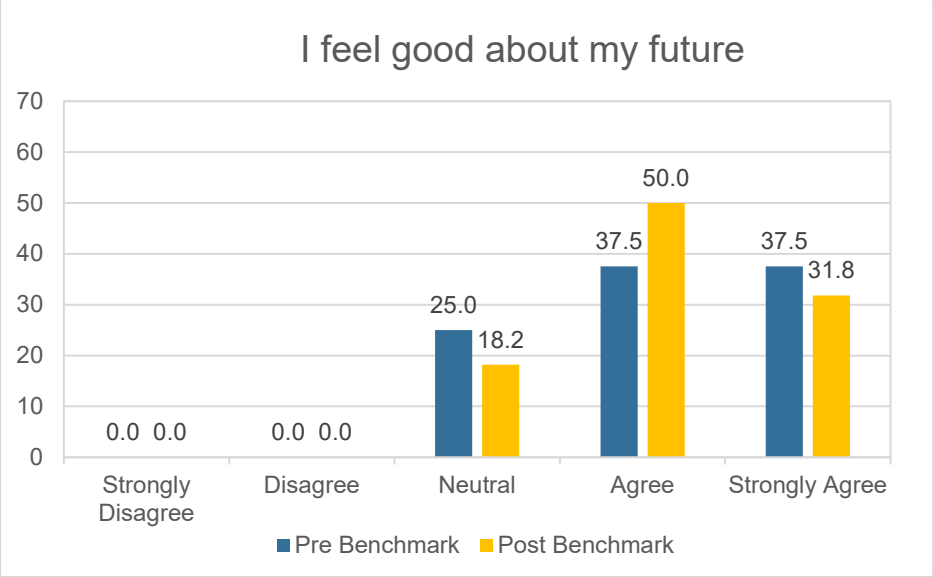
60
50
40
30
20
10
0
3.1
0.0
0.0 0.0
15.6
0.0
53.1
63.6
28.1
36.4
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre Benchmark
Post Benchmark


I feel good about who I am
70
60
50
40
30
20
10
0
0.0 0.0
0.0 0.0
15.6
13.6
40.6
45.5
43.8
40.9
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre Benchmark
Post Benchmark


I feel good about my future
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60
50
40
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25.0
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Strongly Disagree
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Strongly Agree
Pre Benchmark
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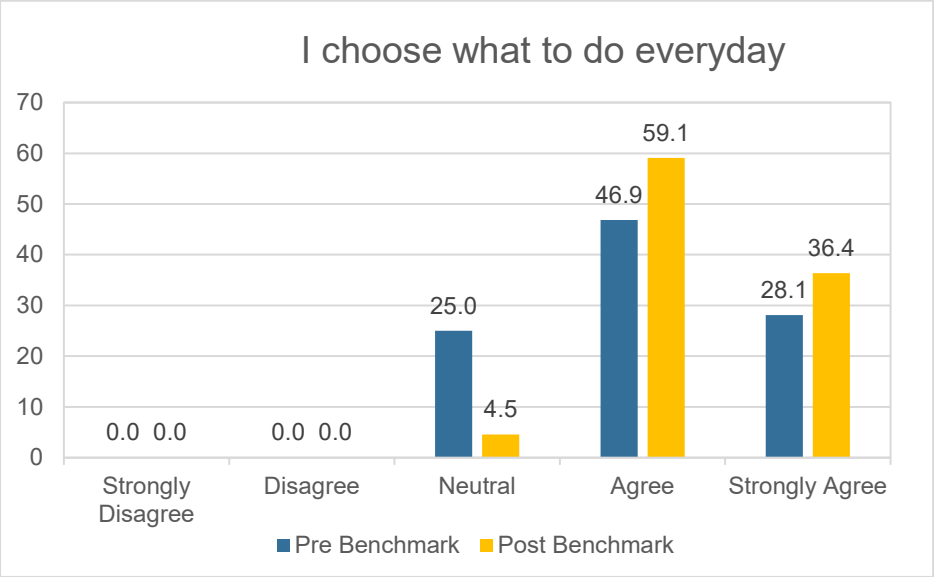
I choose what to do everyday
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50
40
30
20
10
0
0.0 0.0
0.0 0.0
25.0
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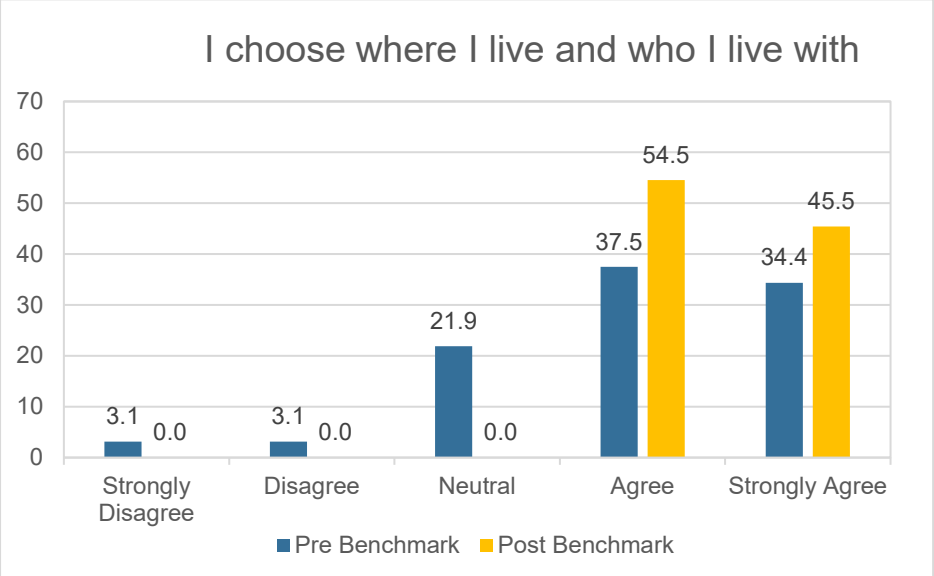
59.1
28.1
36.4
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre Benchmark
Post Benchmark


I choose where I live and who I live with
70
60
50
40
30
20
10
0
3.1
0.0
3.1
0.0
21.9
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Neutral
Agree
Strongly Agree
Pre Benchmark
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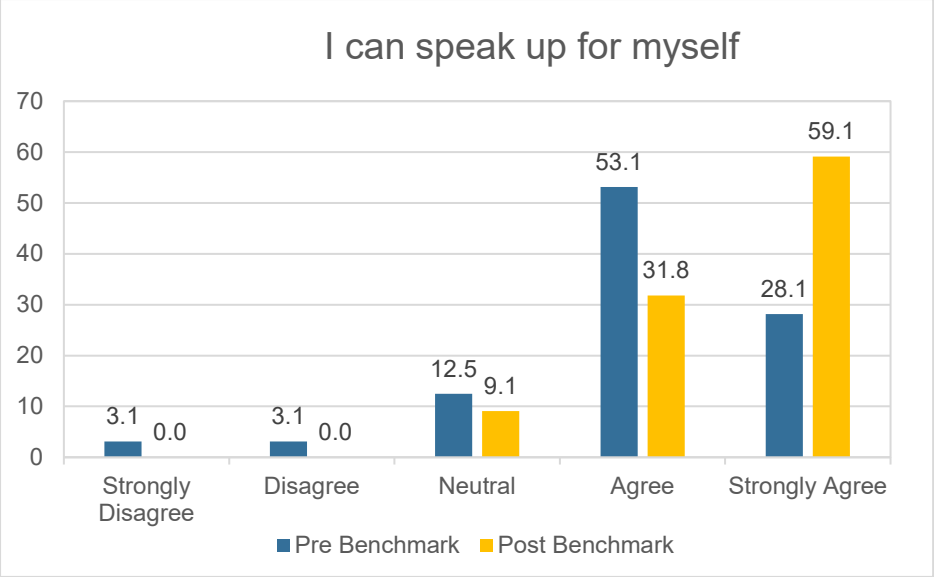
I can speak up for myself
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3.1
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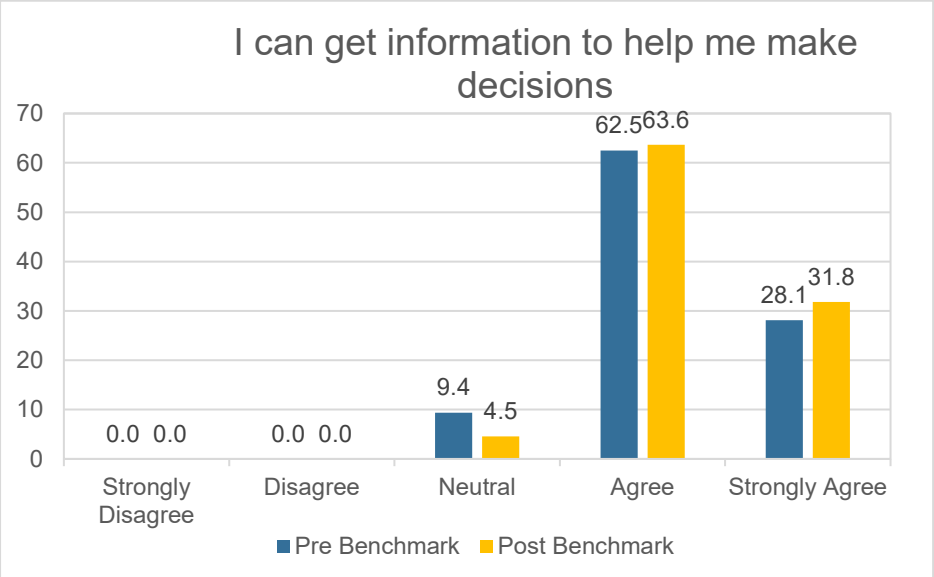
I can get information to help me make decisions
70
60
50
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30
20
10
0
0.0 0.0
0.0 0.0
9.4
4.5
62.5
63.6
28.1
31.8
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre Benchmark
Post Benchmark