SPRC UNSW Social Policy Research Centre

Our Voice SA Reaching Out Project

Final evaluation report

Prepared for: Our Voice SA and JFA Purple Orange

March 2023

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Acknowledgements
Alison Vivian, Tristan Salim, Debbie Knowles, Mikaila Crotty (JFA Purple Orange), Our Voice SA Board and members.

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The Social Policy Research Centre is based in the Faculty of Arts, Design and Architecture at UNSW Sydney. This report is an output of the Our Voice SA Reaching Out research project, funded by the National Disability Insurance Agency.

Suggested citation:
Sandra Gendera, Michelle Bellon, Sally Robinson, Yuvisthi Naidoo, Tim Cahalan, Karen R Fisher (2023). *Our Voice SA Reaching Out Final Evaluation Report.* Sydney: UNSW Social Policy Research Centre.

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Short summary

Our Voice SA is a peer-led self-advocacy group for adults with intellectual disability. In 2020, the group received a 3-year ILC grant to deliver the Reaching Out project. The goal was to broaden their reach so that new people could learn about their rights and speak up for themselves. Our Voice SA works with people who live in the community and in supported accommodation and supported workplaces. Our Voice SA are connected to people with disability across Adelaide and four regional areas of South Australia. This is the final evaluation report for the project.

People with intellectual disability involved in Our Voice SA activities and peer 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. Participants in project activities developed confidence, knowledge and skills to speak up for themselves and peers over time. Finding their voice and understanding their rights were central to living a more self-directed life.

Over the 2-year research period (2021-2023) many peer network groups saw a steady growth in numbers of people attending and growth in people's confidence to contribute ideas, make everyday decisions, and speak out when things were not going well.

Our Voice SA used peer support across all activities. Peer support was an effective way to build connection and self-advocacy awareness of people with intellectual disability. Our Voice SA members took on a range of paid and unpaid leadership and advocacy roles. Group members who were involved for longer were supported to step into formal leadership roles.

The research found that the Reaching Out project was successful in its goals. The group, its members, connections and relations have grown and matured due to new impetus in the group, staff and new strategies to build individual and group advocacy skills and leadership. The group is recognised as having authority and a voice to speak on behalf of a wider community of people with intellectual disability.

Barriers and challenges for people with intellectual disability to be connected to their peers, be heard and listened to by people in decision making positions persist, underlining the importance of continuing the work of Our Voice SA. The structural investment, growth in members, development of relationships and connections that occurred is at risk with a lack of ongoing funding. It would be a major loss for self-advocacy of people with intellectual disability if the progress and impact achieved to date was lost through inadequate investment in Our Voice SA in the future.

Executive summary

Our Voice SA is a peer-led self-advocacy group for adults with intellectual disability in South Australia. The group was founded and is run by and for adults with intellectual disability. Our Voice SA supports its members to feel connected to peers and be part of a group that has a voice. The group builds capacity and rights awareness, skills and confidence to speak up for oneself and for one's peers.

In 2020, Our Voice SA received a three-year Information, Linkages and Capacity Building (ILC) grant to deliver the Reaching Out project (from NDIA, then transferred to DSS). The group wanted to broaden its reach so that new people could learn about their rights and speak up for themselves. Our Voice SA works with people living in the community and living in disability specific (closed) accommodation or disability employment. They reach out to people in Adelaide metro and seven regional areas across South Australia.

Our Voice SA uses peer support (making friends and knowing other people with intellectual disability) across all the activities. The Reaching Out activities are in closed systems and regional areas, peer network groups, capacity building workshops, monthly Our Voice SA and board meetings, biennial conferences, and community consultations with government, the education and private sectors for people with intellectual disability to have a say in things that matter to them and their peers.

This is the final report of the two-year evaluation research about Reaching Out. The research was funded by the National Disability Insurance Agency. The report was written in partnership between staff employed by Our Voice SA, researchers at UNSW Sydney and Flinders University.

The focus of this report is on the future sustainability of self-advocacy and the lessons for the future of self-advocacy by people with intellectual disability.

Impact and outcomes for people with intellectual disability

Having a voice and speaking up

People with intellectual disability participated in peer groups, capacity building workshops, board and Our Voice SA monthly meetings. They said they developed confidence, knowledge and skills to speak up for themselves and peers. Finding their voice and understanding their rights were central to living a more self-directed life, making decisions and speaking out when things were not going well. People said self-directing their life and making daily small and larger decisions contributed to their sense of self and personal growth and trust in their capabilities and decisions.

Being part of Our Voice SA meant that people with intellectual disability had opportunities to share experiences, life stories and ideas, to be consulted and feel listened to and heard by their peers and the broader community. The experiences of peer support and strength as a group contributed to people's sense of connection and identity as a self-advocacy group.

Leadership development and opportunities

Some Our Voice SA members who were involved for longer or who had an interest in self-advocacy were supported to step into leadership roles. These roles included co-producing podcasts and videos, writing for or being interviewed for news articles, participating in and co-design of research, attending conferences, making public presentations and advocating with politicians and other people in decision making positions. Having people with disability in leadership roles fostered their personal growth and learning and increased the impact of the work of Our Voice SA. They also contributed to the sense of impact and identity for the group as a whole.

Recognised and respected in the broader community

Our Voice SA is recognised as having authority and a voice to speak on behalf of a wider community of people with intellectual disability. The group was invited to participate in consultations for government, in research and education, and private market initiatives to improve accessibility and inclusiveness. Invitations increased in frequency and policy significance over time.

Participating in the community and connecting with peers

People with intellectual disability involved in Our Voice SA activities and peer 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. Making connections, new friendships, learning from the 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 self-advocacy groups, meetings and activities.

Respecting, valuing and listening to people

One objective of Our Voice SA is to raise expectations in the community and by people in decision-making positions (government, services and research) about people with intellectual disability, so people feel valued and are respected and listened to. In some workshops and peer networks groups (in places of supported living and work) participants felt encouraged to continue to take part when they knew that their input and suggestions were shared with senior management in a safe and

anonymised way. Participants also felt encouraged when they saw their recommendations put into action.

A mix of structural and organisational culture factors negatively impacted the experience of achieving change, and people with intellectual disability being genuinely listened to. In several of the peer network groups in supported accommodation and employment, meaningful organisational change in response to the ideas generated by workshop groups and peer networks was limited.

Overall impact and outcomes

People with intellectual disability involved in Our Voice SA benefited from understanding their rights and building confidence and skills to speak up. This affected people's lives, everyday decisions, relationships and interactions, and helped them to achieve personal goals.

The project established and built capacity of peer network groups in places where people with intellectual disability live and work. Several peer network groups were already having an impact on organisational policies and practices, and changes were visible. In others, the momentum of acting on advice from the peer support groups and implementing change was slower or stalled.

Effective processes used by Our Voice SA

Our Voice SA has expanded into four regional and three metro areas and five supported accommodation and work settings (closed systems) across South Australia; achieving a primary objective of the Reaching Out project.

Our Voice SA used a multi-pronged approach to engage and expand into regions, where people with intellectual disability were not yet well connected in peer-led groups. This process took a long time to establish. In addition to building on new and existing relationships in the regions, the group employed local staff (country connectors) and locally based peer mentors with disability; publicised the activities in multiple ways; used community venues that were central and accessible; delivered topics and presentations relevant to local contexts and people's interests; created welcoming spaces and developed interactive content that supported interaction and connection building.

In the regions, persistence, locally employed staff, peer mentors, and time were key factors to gain momentum and spread the information in the regions. In metro areas building on existing networks and a service providing space and support for peer networks were key to the success of forming peer groups and running workshops.

Peer support was a central and effective mechanism to foster connection and learning across different Our Voice SA activities. People with intellectual disability participated in peer support networks to meet peers who live in the same accommodation, were linked to the same service or lived in the local area. The Our Voice SA board and group from the metro area meet regularly to make decisions about the direction of their self-advocacy. The small group process appeared effective for engaging people living with intellectual disability, to build capacity and skills in members to advocate and speak out for themselves and others.

Contributors to the success and sustainability of a peer group appeared to be connecting to a service or organisation. Community based peer networks were, over time, less well attended or more likely to see regular members disengage compared to groups linked to an organisation.

Continuously seeking small and bigger leadership opportunities across the different project activities was a successful process in the project. Our Voice SA offered members a growing number of leadership development opportunities and 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; participation in committees and discussions; co-design and co-production of activities and materials for Our Voice activities or the conference, video and audio material.

Peer mentors made an impact on the quality of the project by contributing through sharing their lived experience stories, answering questions, spreading the word through their communities and networks (to help with recruitment), and assisting with meetings and activities.

Our Voice SA is managed and governed by the decisions taken by its board, all people with intellectual disability. The board members hold a range of responsibilities and roles, including managing and oversight of the groups' finances. Over the last two years Our Voice SA invested significant resources to review and revise the constitution and develop easy read materials, eventually undergoing a full update to the constitution. Associate members were added as board members, a significant change which brought people without intellectual disability onto the board. The review process was an important step to ensure that every member was heard and had input into the amendment of the constitution.

The inclusiveness of the board governance grew over time by engaging with accessible information, taking ownership and responsibility for roles and by supporting all members of the board to exercise their voice.

Challenges and opportunities for self-advocacy

Participants in some of the peer network groups and activities in closed systems started seeing changes in their work and living environment, relationships and interactions with other people as a result of changes in policies, practices and expectations towards people with intellectual disability.

Organisational culture and accountability

Challenges to engaging with organisations were where Our Voice SA had no existing relationships, limited trust and understanding of their approach, organisational culture and gatekeeping. The culture of organisations enabled or constrained the potential impact of the groups and development activities, and the impact of self-advocacy.

The peer network groups and activities within organisations appeared to be effective when people with intellectual disability (and the Our Voice SA team) formed alliances with senior decision makers. Managers were central to leveraging their positions with the organisation and administration to address culture and administrative processes. Management and staff turnover affected the opportunity for the impact of the work in closed systems and established organisations.

For the future Our Voice SA could consider implementing additional accountability measures to sustain the impact of peer activities in closed systems and services, for example, easy read material (minutes) which include detail about actions required to respond to change requested.

Maintaining momentum

It took considerable effort – investment of resources, time and persistence – to establish relationships and networks, reach into regional areas and some closed systems. While many of the regional and metro peer groups were experiencing a significant growth in numbers and regular attendance, others were seeing a decline in attendance over time. Many reasons explained the declining and fluctuating participation. They included structural reasons (limited funding or support to attend), environmental (belief that there is ‘nothing on’ in the regions), and personal factors (preference for some activities). The research found that relationships based groups, peer groups and activities organised in a partner organisation were more sustainable over time compared to community based groups.

Future sustainability of self-advocacy

Self-advocacy by and for people with intellectual disability requires resources: suitable venues (places and spaces, technology) to meet; paid staff to facilitate, coordinate and organise; administration (HR and payroll support) for staffing; funding

to support members to attend local meetings, state and interstate systemic advocacy events; delivery of conferences and capacity building activities. Since the introduction of the NDIS, the organisation has successfully applied and received ILC grants to sustain and expand their reach, develop their name and profile in the community.

The research demonstrated that Our Voice SA's Reaching Out project achieved impact and outcomes for people with intellectual disability in South Australia. The benefits included connections with peers, improving practice, building leadership capacity, and being heard and listened to by people in decision making positions. The program also manages persistent barriers and challenges faced by people with intellectual disability. The capacity of the members, development of relationships and connections requires continued organisational support to extend the impact of the peer support approach. The community faces the risk of losing that peer support and self-advocacy capacity if ongoing funding sources are not secured.

1 Our Voice SA Reaching Out Project

1.1 Background

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 with intellectual disability. The purpose of Our Voice SA is to increase visibility, voice and skills of people with intellectual disability in community, civic and public life through building leadership.

Our Voice SA supports its members to,

- feel connected to peers and be part of a group that have a voice. People with intellectual disability are listened to and respected in the community
- people know their rights, grow skills and confidence to speak out about the things that matter to the person and the group
- to participate in community, civic and public life through leadership building.

The peer-led group has over 100 active members with disability and associate members, like family and friends. The peer-led self-advocacy group have a board that manages the group's finances and makes decisions about how to achieve the group's goals. About 20 core members take part in monthly Our Voice SA meetings and board meetings.

Our Voice SA is an incorporated association. This means they 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). Many of the long-standing members have experience of living in disability specific (closed) accommodation and moved to self-directed living in the community.

In 2020, the self-advocacy group started a project called *Our Voice SA Reaching Out.* The three-year project funding was an Information, Linkages and Capacity Building (ILC) grant by the National Disability Insurance Agency. The funding was extended until mid-2024. The aim of the *Reaching Out* project is to increase the reach of Our Voice SA and connect people with intellectual disability with their peers, get people involved in self-advocacy work and build awareness of their rights. Our Voice SA works with people living in the community and living in disability specific (closed) accommodation or disability employment. They reach out to people in metro and four regional areas across South Australia.

1.2 Project activities and processes

Our Voice SA organises activities to achieve the project goals (Table 1).

Table 1: Our Voice SA Reaching Out project logic

Outcomes
People with intellectual disability in metro and regional areas in the community and where people live and work (supported accommodation/employment settings, closed systems): • Gain confidence, knowledge and skills to advocate for self and peers • Have a voice and speak up • Participate in the community • Experience equal rights and opportunities • Have connections, friendship and support with 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 • Peer support • Expand into regional areas and closed systems • Leadership roles • Peer mentoring • Board and governance
Activities
People with intellectual disability, staff, Our Voice SA and JFA Purple Orange organise and deliver: • Peer network meetings • Our Voice SA monthly meetings • Community consultations • Workshops • Conference

1.3 Our Voice SA activities

Peer group meetings

Our Voice SA organised peer groups in twelve locations. The peer groups were held in a place of accommodation or a service, some were held in the community, like a community centre. Four of the locations were in regional areas, the others are in and around Adelaide. The aim of the peer groups was to connect and support people with intellectual disability in a local area or within a place of accommodation or work setting who were not yet linked. Some peer groups existed before Our Voice SA got involved; other groups were started by Our Voice SA.

Our Voice SA monthly meeting

Our Voice SA met monthly to discuss how they organise themselves, how to reach their stated goals (i.e., planning of the conference, interstate engagement and representation at self-advocacy events) and plan for the future, such as putting forward proposals and ideas to the Our Voice SA board.

Community consultations

Members of Our Voice SA were regularly invited to have a say in things that matter to them and their peers. Examples included consultations with the government, like the NDIA, the Taskforce on Restrictive Practices, meeting members of Parliament to discuss employment opportunities for people with disability, and consultations and contributed to research with private and state-run organisations, like SA Water, the Australia National University and Flinders University. Our Voice SA held private and public sessions with the Royal Commission into Violence and Abuse of People with Disability, focused on violence at home.

Workshops

Our Voice SA run a series of seven capacity building workshops, delivered to the same group of people over a period of approximately 3-6 months, which varied by location. In the workshops people with intellectual disability could grow their knowledge, learn more about rights, learn from and connect with each other, and gain confidence and skills to make decisions and speak out about things that matter to them. The workshops were designed to help people identify what mattered to them and to their peers. Between 2020 to 2022, Our Voice SA delivered 56 capacity building workshops.

Conference

In 2022, Our Voice SA organised the second South Australian conference by and for people living with intellectual disability titled, *Be the Boss of your Life*. The conference was held at the Hilton Hotel and over 120 people with and without

disability attended. 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 the services they offer and how they can support people with intellectual disability to take part. A representative from the NDIA engaged with conference attendees in a Q&A session.

1.4 Processes

Peer support

Our Voice SA used peer support as a central building block 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). There are several aims in using peer support as a central process, including to build the authority of people with intellectual disability; to generate confidence in other people with intellectual disability by being encouraged and supported by a peer; to provide employment and capacity building opportunities for peer workers; and to demonstrate the contributions that peers make across multiple levels of practice.

Reaching into regional areas and places of living and work

Our Voice SA expanded into regional areas and supported living and work (closed systems) where people with intellectual disability were not yet or not well connected in peer-led self-advocacy groups. They used strategies like building relationships and working with local workers and people with disability, employing peers with disability as peer mentors to deliver activities and expand networks.

Leadership

Our Voice SA supported people with intellectual disability to take on and grow in their leadership skills and roles. Leadership could take on many forms, making changes in one's own life and sharing stories with peers and the broader community (i.e., radio, writing, conference, podcasts), representation at interstate and self-advocacy events, participation in consultations and hearings, and public speaking. Within all of the Our Voice SA activities people with disability were supported to develop their leadership capacity.

Peer mentoring

Our Voice SA recruited and trained paid peer mentors. Peer mentors were people with intellectual disability who functioned as a 'connector' or a 'guide' to newer Our Voice SA members. They spoke to people interested in self-advocacy about their rights, answer questions, and shared information about planned activities. Peer

mentors also attended workshops and co-facilitated the delivery of content and assisted in planning events and meetings delivered by Our Voice SA.

Board and group governance

Our Voice SA has a board of 10 elected members who run the group by discussing ideas and voting on options. The board made decisions about the future directions of Our Voice SA and manage the groups' finances. The board 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, without intellectual disability, can be elected to the board and vote at meetings.

1.5 This study

Study aims and questions

This is the final report of research about Our Voice SA Reaching Out. The evaluation research was funded by the National Disability Insurance Agency.

The research asked three questions:

1. **What impact does Our Voice SA have on people with intellectual disability**, and how does the project build members capacity to self-advocate and connect?

2. **What processes were effective for the project to connect** people with disability and peer leaders to networks of peer support and self-advocacy?

3. **What barriers, challenges and opportunities were evident, resolved and remain in the project process**? How might these contribute to better ways of working with people with intellectual disability, and accommodation providers to increase opportunities for self-advocacy and connection?

Data sources, methods and reporting

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

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

- Significant change stories

- Observation of Our Voice SA activities

- Interviews with members and staff
- Program information from Our Voice SA, including the Personal Growth Index Scale (PGIS) survey data.

The methods and analysis are described in more detail in the Appendix.

The report was written in partnership between staff employed by Our Voice SA, researchers at Flinders University, Adelaide and UNSW, Sydney. The focus of this report is on the future sustainability of the self-advocacy group and the lessons from Our Voice SA for the future of self-advocacy by and for people with intellectual disability.

Any names in the report have been changed to protect privacy.

2 Impact and outcomes for people with intellectual disability

This section presents findings about the Reaching Out project impact and outcomes for people with intellectual disability.

2.1 Having a voice and speaking up

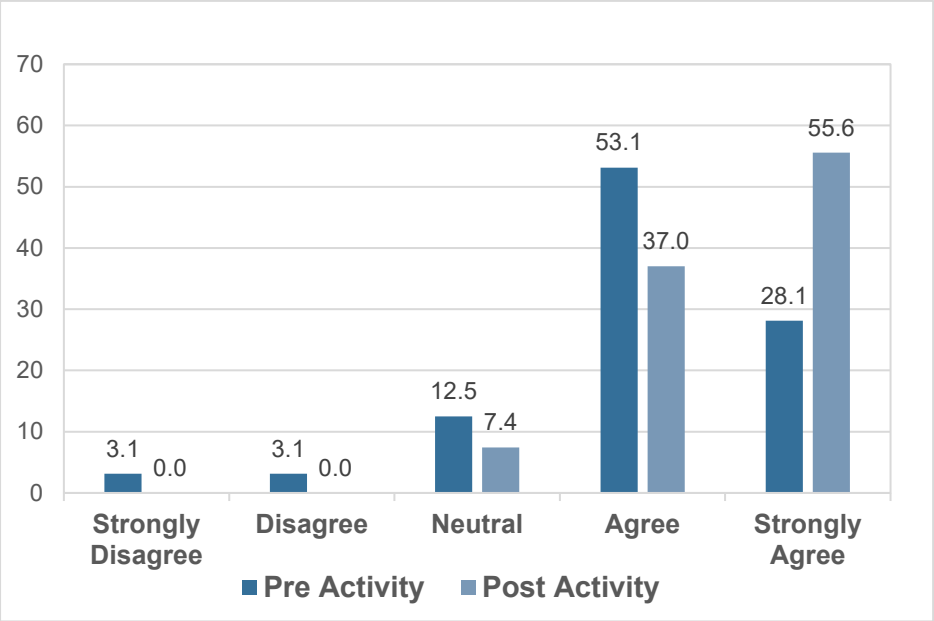
The aim of the Reaching Out project was to promote and build capacity for people with intellectual disability to lead more self-directed, connected and included lives. They seek to do this by resourcing people directly and connecting them with peers and by promoting changed expectations in the community and people in decision making positions.

Increased confidence, knowledge and skills to advocate for self and others

People with intellectual disability participated in peer groups, capacity building workshops, board and Our Voice SA monthly meetings. They said they developed confidence, knowledge and skills to speak up for themselves and peers. Finding their voice and understanding their rights were central to living a more self-directed life, making decisions and speaking out when things were not going well.

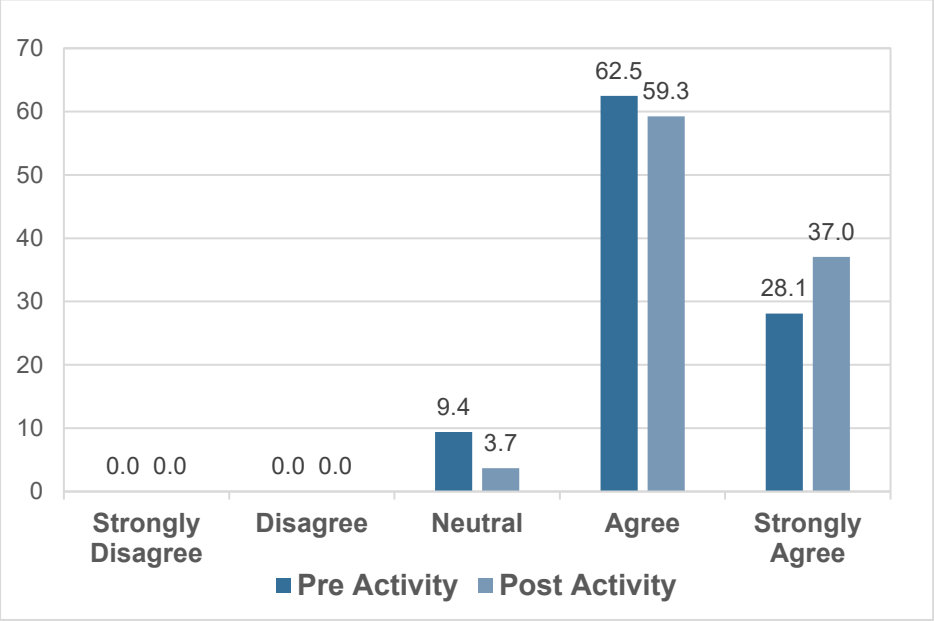
The analysis of responses, collected before starting and after completion the 3-6 month workshop series, indicated the positive impact of the capacity building activities on a range of personal growth measures. This included gaining the confidence to speak up for themselves and the capacity to find information to help with decision making. More people (55.6%) said that they strongly agreed that they could now speak up for themselves following the workshop, compared to 28.1% before the workshop (Figure 1). While 96.3% agreed that they could get information to help make decisions, up from 90.6% before the workshops. (Figure 2).

Figure 1: I can speak up for myself (per cent)



Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)
Sample: Pre-Activity (n=32) / Post Activity (n=27)

Figure 2: I can get information to help me make decisions (per cent)



Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)
Sample: Pre-Activity (n=32) / Post Activity (n=27)

People said self-directing their life and making daily small and larger decisions contributed to their sense of self and personal growth (who I am and what I can do), and trust in their capabilities and decisions.

> Often the people around us … try to take over what they think is best for us. We often tend to rely on everyone else and think that we are not capable of

> making choices. But we are. We are just like everyone else. We may not always make the right choices, but that's how everyone learns, by making mistakes. (Simone, Our Voice SA member)

> When you are not your own boss and you let other people [make decisions for you] it doesn't make you feel very good about yourself …Now, I have become independent and realised I can be 'My own boss' and do what I want. I can choose and make my choices. (Elsa, Our Voice SA member)

Peer mentors emphasised how becoming part of the self-advocacy group helped increase their confidence and skills, like public speaking, preparing presentations and meetings. Their personal growth continued with the new experiences and opportunities people had as part of their role. Personalised support and investment of time helped too. In addition, people said the group helped them to "see and hear" other members "doing great things" and sharing their stories.

> Our Voice has changed my life, I have more confidence now, I speak up …. Sometimes we have issues with the staff [where I live], or services, and people with disability can be shy, they don't want to make a fuss … Since, I have come on board, and am part of Our Voice … I have seen us all grow. It's helping us get us out of our shell, get out of our comfort zone. (Isabella, peer mentor)

Connections, identity and relationships

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

Participants explained how people with intellectual disability benefited from the Our Voice SA group and activities. Sharing stories, learning from and supporting each other, working through a problem "as a team" as well as having fun together were all core parts of the group experience. These experiences of peer support and strength as a group contributed to people's sense of connection and identity as a self-advocacy group. One person said, "It's electrifying. It's powerful … having a voice, all as one." (Our Voice SA member).

2.2 Leadership development and opportunities

A wider objective of Our Voice SA is to raise expectations in the community and people in decision-making positions (government, services and research) about people with intellectual disability. The reason is so that people feel valued and are respected and listened to.

In some peer groups in supported accommodation and work settings 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. Participants also felt encouraged when they saw their recommendations put into action. Senior management involved in some of the peer network groups said they valued the input from people with intellectual disability and opportunity to learn from the group's ideas and advice.

In organisations where input and feedback were valued and respected, participants said they saw improvements to the services, systems, communication pathways, investment in the peer support group (support for people to attend, staff time for group organisation), and encouragement to expand the group further. One service that had taken on board many of the suggested changes, the organisation gave the peer support groups reasons, justifications and timeframes for the changes that were still waiting for action.

Stepping into leadership roles

Some Our Voice SA members who were involved for longer or who had an interest in particular aspects of self-advocacy were supported to step into leadership roles. These roles included co-producing podcasts and videos, writing for or being interviewed for news articles, participating in and co-design of research, attending conferences, making public presentations and advocating with politicians and other people in decision making positions. Having people with disability in leadership roles fostered their personal growth and learning. At the same time, they also contributed to the sense of impact and identity for the group as a whole. One long-standing member, who was actively involved on the board, in research and in the co-production of peer resources explained,

> Things are changing for people with disability. We have a voice!! … My work with [Our Voice] helps me to believe in myself. I worked in a sheltered workshop [disability employment] before, now I am an advocate … I love it! (Shane, Our Voice SA member)

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

Shane (not his real name) has been a part of Our Voice SA for almost 4 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.

Recognised and respected in the broader community

Our Voice SA is recognised as having authority and a voice to speak on behalf of a wider community of people with intellectual disability. The group was invited to participate in diverse consultations for government, in research and education, and private market initiatives to improve accessibility and inclusiveness. Key government consultations included two NDIS policy reviews, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and university research projects. The growing number, depth and significance of consultations and input into research and policy over time meant that members involved in the core group felt respected as a group, as one member underlined, "everybody knows who we are".

2.3 Participating in the community

As well as building rights awareness, self-advocacy and group advocacy skills, Our Voice SA also delivered information and invited guest speakers on a wider range of topics. Participants in workshops, peer networks and monthly meetings said the group meant they had access to information and tools they needed on topics such as how to participate more equally in community life, how to stay safe and how make complaints. Importantly the information was provided in accessible formats. Presentations covered topics of healthy living and wellness, the meaning of home, online and cyber safety, being money smart, and resolving issues about the NDIS.

> Today I have learned what home means to me and the group! Home is where I am loved! (Workshop participant)

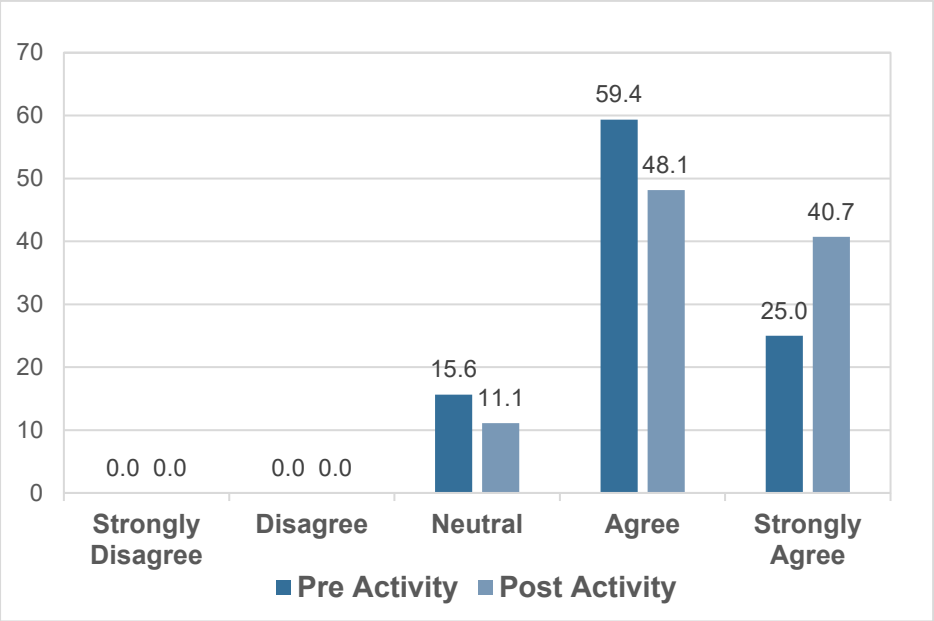
> The topics in our monthly meetings are also changing. Recently we started exploring the issues people have with the NDIS and how to resolve them. (Our Voice SA peer mentor)

Some Our Voice SA members said being part of the group and the activities was an important part of their social network and participation in their community.

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

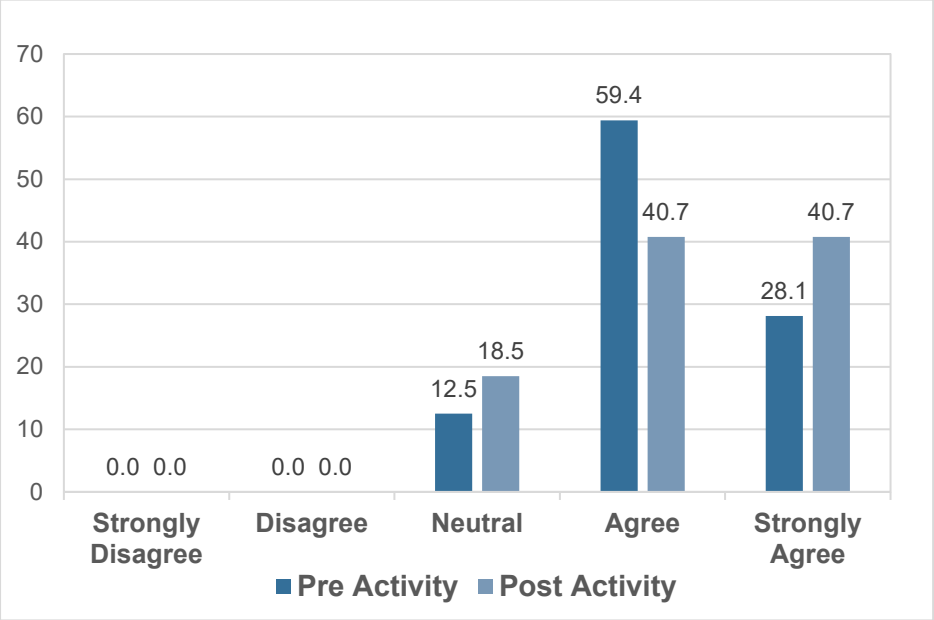
People said they were taking the skills and confidence they learned in the meetings and groups into their own life as well as to their peers and communities. Isabella, a peer mentor, mentioned that she was “helping [my] friends, who live in disability houses … I am helping them with their lives … I give them ideas”. The analysis of survey responses, collected before starting and after completion the 3-6 month workshop series, show that participants were more confident about their capacity to reach their goals according to the surveys before and after the workshops (Figure 5) with 40.7% strongly agreeing with the statements about knowing what do (Figure 4) and having a plan to execute their goals (Figure 5).

Figure 4: I know what I need to do to reach my goals (per cent)



Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)
Sample: Pre-Activity (n=32) / Post Activity (n=27)

Figure 5: I have a plan to reach my goals to change in my life (per cent)



Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)
Sample: Pre-Activity (n=32) / Post Activity (n=27)

Participants in the workshops, peer network groups and meetings spoke about other changes they had made in their daily life. Examples were:

- making daily life choices – which grocery store to go to, planning a meal, going to new places independently

- setting boundaries in relationships – with paid support workers, family, housemates, neighbours
- speaking up when they were unsatisfied in their employment or living situation.

Some participants said they made bigger goals like applying for work or further education, attending job interviews and finding paid employment, moving in with different people or moving out of home.

Figure 6: Life changes for a new member, Monika

Monika (not her real name) is a newer member of Our Voice SA. She attended the Conference, Be the Boss of Your Life in 2021. Throughout 2022, she attended general meetings and peer support groups where she lives. Monika shared her story about how she learned to use her voice and stand up for herself.

"*I've grown confidence and come out of my shell. You've got rights to speak up."* Monika shared an example of her newly gained self-advocacy skills from Our Voice SA and how she made use of them in her daily life. "*My support coordinator is wrong, what she said to me … she offended me*". Monika explained the strategies she learned to use to address this situation, first to use new communication cards to communicate her concern with her support coordinator, and if this did not work, seeking the support of an Our Voice SA team leader. "*I've built my confidence well*."

Monika described Our Voice SA, "*They help people to learn they have rights, know about services, and what they can do"*. She gave examples like learning more information about the NDIS and having the opportunity to speak with Natalie Cook a State MP, and other updates about services in her area. Monika said how Our Voice SA members also gave her feedback on services she could use.

Monika said she was invited to present her story at a 'My Journey before the NDIS and now' at the Speak Out conference in Tasmania together with other Our Voice SA members, and she was excited about this opportunity.

Monika said she was mostly satisfied with her engagement and opportunities to learn through Our Voice SA. In the future she wanted to see some workshops and meetings go longer, "because there is not enough time to ask all questions", and more creative or art workshops.

Monika's message about the importance of Our Voice SA was clear: people with disability do not get listened to in the community, and people get shut down a lot. Instead, people should raise their voice and use any form of communication to get their point across. "*I love Our Voice SA…They need to spread the word. Not enough people know about them."*

Impacting change

A focus of the Reaching Out project is to work with people with intellectual disability where they live or work in closed accommodation and disability employment. Our Voice SA engaged with five large to medium accommodation and employment providers to establish new peer groups, expand existing groups, and strengthen the voice, capacity and processes for people with disability engaged in the self-advocacy groups. Table 2 Appendix presents the numbers of participants in these groups over time. A number of groups built momentum over time and positively influenced changes to organisational practices, policies and expectations towards people with disability by management and staff. These changes included: managers building capacity to prepare easy read information, changing organisational complaints processes (so they are easier and more confidential), up-dating welcome packs, and making safety improvements to environments and buildings, such as better lighting in dark spaces. One organisation also introduced peer supervisors within their supported disability employment after receiving feedback from the peer network. The organisation has trained people with intellectual disability to take on leadership roles within the workplace.

A mix of structural and organisational culture factors negatively impacted the experience of achieving change, and people with intellectual disability being genuinely listened to. In several of the peer support groups in supported accommodation, meaningful organisational change in response to the ideas generated by workshop groups and peer networks was limited.

2.4 Summary of outcomes and impact

The Reaching Out project had an impact self-advocacy, which grew demonstrably over the last two years (see Appendix Table 2). The impetus from the Reaching Out project, combined with strong leadership from the board, project manager and staff have added substantial momentum to the activities of the organisation. The outcomes demonstrate considerable growth in numbers, members' confidence and leadership, impact in current policy and practice issues in South Australia and nationally, and community and peer connections for people within intellectual disability.

People with intellectual disability are involved in several ways, through the Our Voice group, as members, peer mentors and connected in peer groups in regional areas and supported accommodation or employment. They have benefited from capacity building, peer connections and finding their voice to speak up. Understanding their rights and building confidence to speak up has changed people's lives, everyday

decisions, relationships and interactions, and helped people to achieve personal goals.

The project has invested to establish and build capacity of peer support groups in places where people with intellectual disability live and work. Peer support groups were having an impact on organisational policies, practices and changes were visible. In others, the momentum of acting on advice from the peer support groups and implementing change has been slower or stalled.

People with intellectual disability involved in Our Voice SA benefited from understanding their rights and building confidence and skills to speak up. This affected people's lives, everyday decisions, relationships and interactions, and helped them to achieve personal goals.

The next section of the report will look at the processes used in the Reaching Out project and examine factors helping and hindering the success of the project.

3 Effective processes

3.1 Reaching out

Over two and half years, Our Voice SA has expanded into four regional and three metro areas and five places where people live or work (closed systems) across South Australia, achieving the primary objectives of the Reaching Out project. They employed a variety of strategies to build trust, connect with and engage local people with intellectual disability, services, stakeholders, and gatekeepers.

Relationship and trust building was at the centre of the success of the reaching out process. This approach included accessing closed systems, building on past relationships. Our Voice SA workers continued to return to places and services to show presence, genuine interest, offer solutions and answer questions, identify and speak to key people in charge or well connected to develop and strengthen trust and relationships.

Continued contact over time to gain the support and interest of key people in closed systems and people with connections and networks in regions meant that Our Voice SA could set up the peer groups and workshops. The process to establish the activities and groups was not linear. Instead, it had stages of contact, waiting and growth. The process was influenced by fluctuations in staff, shifting priorities and dynamics within contact organisations. The following story of change is from a supported employment provider where the Reaching Out project established a peer support group for employees with intellectual disability.

Figure 7: Capacity building workshops in supported employment

At the start of the Our Voice SA Reaching Out project, a large supported employment service approached Our Voice SA to help them set up a group and develop employees' skills and knowledge about their rights and confidence how to speak up and give feedback. The service did not have formal processes to receive feedback from their employees.

Our Voice SA met with a group of employees with intellectual disability. Many of them 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 develop workshops building employees' capacity around rights and providing feedback to the organisation and its board. Our Voice SA ran seven workshops focusing on self-advocacy, human rights and decision making across several life areas.

Initially, it was difficult to draw out responses from the 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 apply the ideas of speaking their mind, trusting in their abilities and expertise. Over time, it was easier to involve participants in conversations and collect critical ideas about how their employer could improve the working conditions, social aspects of their workplace, health and safety in their working environment.

Towards the end of the workshop series participants 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."

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

The organisation committed to continuous support for the peer network at an organisation level. Our Voice SA were independently facilitating the meetings. After feedback from the peer network, the organisation implemented an annual feedback survey for all supported employees. New initiatives following advice from the peer network on how to hear the voices of other supported employees were a peer led bulletin and suggestion box operated by the peer network.

Our Voice SA used a **multi-pronged and layered approach** to engagement and expand into regions, where people with intellectual disability were not yet well connected in peer-led self-advocacy groups. This process took a long time to establish.

> It took over a year to get momentum in the regions. There was some coaxing involved. In some, we just had to keep going there, again and again …We did not take 'no’ as an answer! (Our Voice SA worker)

In addition to building on new and existing relationships in the regions, the group employed local staff (country connectors) and locally based peer mentors with disability; publicised the activities in multiple ways; used community venues that were central and accessible; delivered topics and presentations relevant to local contexts and people’s interests; created welcoming spaces and developed interactive content that supported interaction and connection building (e.g., disco night) .

Locally based **peer mentors with disability** were particularly effective in the regions.

> Employing and building the capacity of the [local] peer mentors has been fantastic! It's worked tremendously for engaging the regions. Having a person with disability co-facilitate, plan and organise the meetings, means ...we have that co-design input in-built; their input ensures we personalise the workshops to the local contexts …When peer mentors share their personal stories … that's very relevant for the people attending. Attendees have told us they really connected with the personal stories. (Our Voice SA facilitator)

In the city areas building on existing networks and a service providing space and support for peer networks were key to the success of forming peer groups and running workshops.

Input from Our Voice SA regional and metro staff revealed **ongoing structural challenges for** people with intellectual disability in regions and closed systems to participate and connect in self-advocacy groups. The main problem was low and irregular attendance. The challenges were similar, but the factors affected some areas more than others.

The problems that staff identified were: concerns around Covid, or the need to isolate; getting information to participants; transportation; restricting information by supporters/workers and limited funding/support to attend group meetings; difficulty finding a suitable time for meetings to suit everyone; low attendance making for an uncomfortable environment for some people; and challenges finding suitable community venues, especially in regional areas.

3.2 Peer support

Peer support is a central **mechanism to foster connection and learning** across the Our Voice SA activities. People with intellectual disability take part in peer support networks to meet peers who live in together, nearby or are linked to the same service. The Our Voice SA board and group come together from a broader metro area regularly to make decisions about the direction of self-advocacy. Together they speak up about things that matter to them in their life, learn and share ideas about their place of work, home and local community. The Story of Change (Figure 8: Impact of peer support groups) below demonstrates the impact of a peer support network on individual group members and the positive impact peers can have on their environments and interactions with others.

The small group process appears to be effective for engaging people living with intellectual disability to build the capacity and skills of members so they can advocate and speak out for themselves and others. Originally most meetings were held face to face in familiar and at an easily accessible place with refreshments provided. Since, the Covid pandemic, Our Voice SA trialled more technology and

mixed online and face to face meetings so that members had more choice about how they take part and reach people who have the support to use online technology.

Figure 8: Impact of peer support groups

Speaking up and seeing a difference

Matthew is a confident member of the group. At first Matthew was hesitant about whether anything would change by speaking up in the group organised in his 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 service.

Soon after the meetings began, Matthew 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. Matthew 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 service] by speaking up … We are now being told when things are happening, and management are asking for our advice.

Matthew 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". 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 together.

Matthew volunteered to speak in person to the employment provider Board representing the voices of his peer support group.

Peer groups have also had fluctuations in the number of people attending over time. Some groups, especially in the regions, have seen considerable growth in numbers, with some activities catering up to 50 people in a single event. Other groups however have reported falling numbers of attendees, according to the Our Voice SA staff.

Factors that enhanced sustainability were consistency of information, inclusive and skilled facilitation and organising, following up attendees and contact potential members and support to attend. A key factor seemed to be connection to a service or organisation. Peer groups and networks linked to an organisation were more

stable than community based groups that tended to become less well attended or have some members disengage over time.

3.3 Leadership development and roles

The purpose of Our Voice SA is to increase visibility, voice and skills of people with intellectual disability in community, civic and public life through building leadership. Our Voice SA offers members a range of leadership development opportunities and leadership roles.

Leadership for Our Voice SA members means many things. First of all, it was about finding one's voice and having confidence to speak up and make everyday decisions.

Figure 9: Story of change: Practising being in control

This story of change is told by a locally employed facilitator (country connector) of a regional peer support group. Our Voice SA established the local peer network for people with intellectual disability who were not yet connected. The group meets once a month and provides a range of opportunities (workshops) and community activities.

The people who come to the Our Voice SA meetings mostly live in supported accommodation and work part-time in disability employment. Many people in the group attend day options with the same group of people. Some have few opportunities to meet new people or get out and about and feel part of their local community. The facilitator of the group noted, over time she had observed,

> a marked growth in confidence [among the attendees]. People told me that they feel valued in the group, they are learning to make small everyday decisions, for example, about coming to the group or ordering food, trying out new experiences, outside their familiar routines.
>
> It starts as small steps, practising and knowing what this feels like to be in control of your choices and speak up, to have a say. To be seen out in the community and to have others stop and say hi to people when we are in town is not an everyday experience for some. People learn they too can be active in the community and hopefully feel safe and welcomed.

Asked to reflect what made the changes possible the facilitator said,

> Small changes come about because people are exposed to new experiences and opportunities that are accessible and not overwhelming.

> Repetition, high quality information in a similar easy read format, and making the activities and learnings fun, all this helps people to learn and remain interested. We encourage people to 'practice' what they learn, so the new information is really understood on that experiential level, and put into practice, such as decision making.
>
> The small steps and decisions lead to larger steps. It helps a person to create strength in their ability to trust that they can make good decisions and build confidence that their choice is valid.

Leadership roles in Our Voice SA included: being part of the decision making and voting process at board (and monthly) meetings; participation in committees and discussions; co-design and co-production of activities (workshops) and materials for Our Voice activities, like the conference, speeches, peer material in form of audio-/video recordings about the group's impact; supporting newer members to understand how rights could apply to their life; systemic advocacy, meeting senior members of state and federal parliament and other people in decision making positions; engaging with private sector and university research; sharing stories in a wide range of mediums to reach a broader audience including radio and newspaper interviews, and contributions to news articles.

Members of the core group highly valued the leadership opportunities from the project, its governance and self-advocacy activities. They were the board members, active members in the monthly meetings and employed peer mentors. Participants in the workshops also took up leadership roles. Examples were speaking and presenting to the board of their accommodation or employment service on behalf of their group. Some of these leadership contributions were formal roles. The project team also promoted smaller opportunities, such as asking members to chair peer network meetings, read Welcome to Country or take notes at meetings.

The project adopted the approach of continuously seeking small, big, formal and informal leadership opportunities in the various Our Voice SA activities. The leadership roles were sustainable due to the gradual, personalised development of each person's capacity and confidence in the roles. The success of the approach relied on highly skilled project staff. A senior staff member commented,

> The Our Voice SA team are fabulous, they know how to identify a members' strengths, support them to fill a particular role, may it be for a day or a formal ongoing role…They are invested and know all the people who are employed and central to the project, and how to bring the most out in all people". (Our Voice Manager)

People with intellectual disability developed a sense of authority through the wide range of leadership opportunities offered through the Our Voice SA governance and activities (consultations, peer mentoring, public speaking, being known in the community, systemic advocacy). Members also developed new ideas for the project over time. When they took on leadership roles, they understood that they had something important to say and people would listen to their ideas.

Over the two-year evaluation, growth in participation in a wider range of Our Voice SA members and participants became evident. Leaders came to include newer and long term members, younger and older, women and men and people living in metro and regions. Many members have demonstrated growing confidence in their decision making, voice, trust in the value of their ideas and contributions, and understanding of the responsibilities that are part of a formal role.

The success in developing leadership and creating these opportunities in and outside the group was evident in the growing number of consultations and public and private invitations, awards and recognition of the group and its members.

3.4 Peer mentoring

Our Voice SA supported three people with intellectual disability in the metro area and two people in regional areas to take up paid peer mentor roles. Peer mentors are an important part of the activities. Their role added lived experience to the content and presentations or workshops, opportunities for co-design of material and events, employment opportunities and leadership development. They generated a greater sense of connection and relevance for attendees.

The importance of the contribution from peer mentors grew over time. Peer mentors shared their stories, answered questions, spread the word of the groups in their communities and networks to help with recruitment, assisted in setting up meetings and activities. The peer mentors functioned as a connecting link for their peers.

Figure 10: Story of change: Growth in a peer mentor

Simone is a newer member to the Our Voice SA self-advocacy group, she has been part of the group for over a year now. In the past she spoke in public and presented at workshops. The paid Peer Mentor role opened up new opportunities for her personal growth.

> I help set up the monthly peer meetings, they are at the local hotel. I do talks about my favourite things. I help with the meetings…I put names on paper, I order the food, choose the music…different and new jobs every time.

Asked about what she liked about her role in facilitating the groups Simone said, "I really like helping [name], really! I like help organise the meetings!"

As part of Simone's peer mentor role, she was invited by the team to join them in Adelaide. Simone said that travelling to Adelaide without her parents or family had been a new experience for her, and it was "quite exciting". In Adelaide Simone took part in a peer mentor training. "I had to learn a lot of new things."

Simone and the other group facilitator Tina observed how having Simone at the meetings helps less confident, shy participants connect to the group. People who may not be confident to speak up or add their ideas openly in the group seek out Simone at the breaks and put forward their ideas to her directly. "I am like a good friend to the other people, they come and ask me questions, I try make them feel comfortable [at the meetings]."

Asked why she thought other people with disability were attending the group meetings and numbers of attendees were rapidly growing in regional areas, Simone noted,

> More people are coming now, many more. I think the food is good, we do fun things, like we organised a Pyjama Party the other night, and we always find new and interesting things to talk about, like…cyber security.

Our Voice SA recruited, hired and supported the personal growth of peer mentors. The role opened up greater responsibilities and opportunities for mentors to present, organise, travel – including interstate, facilitate aspects of delivery and co-design content. Peer mentors who attended the Tasmanian self-advocacy Conference "Speaking Out" said it as a life-changing experience to learn from other people and have their own expertise valued.

The Our Voice SA team emphasised the importance of developing peer mentors' capacity, recognising it was a complex task, knowing how to balance opportunities for growth and more responsibility at the right pace for the person.

The peer mentor roles may be currently underutilised in the project. The peer mentorship process could be further strengthened by offering facilitator capacity training and development, so mentors could gradually take on more complex responsibilities in delivering content and information, eventually demonstrating greater leadership by people with disability.

The project could review the peer mentoring process and assess how these roles could be further developed, how hierarchies in meetings could be reduced, and peer mentors supported to further develop their voice.

3.5 Board structure and functioning

The decisions of the board govern Our Voice SA. The board members hold a range of responsibilities and roles, including oversight of the groups' finances.

Over the last two years Our Voice SA reviewed and revised the constitution and developed easy read materials and a full update to the constitution. The updated constitution was developed with input from the board, a legal consultant, and facilitated by the Our Voice SA staff. The review process was an important step to ensure that every member was heard and had input into the amendment of the constitution.

A major change in the constitution was allowing people without intellectual disability, associate members, to be voted onto the board. Once an associate member is voted to be part of the board, they have voting rights at board meetings, similar to full members (people with intellectual disability).

While the review process had been time and resource intensive, the board regarded it as a highly positive process and development for the self-advocacy group. The outcomes observed from the process included: board members developing greater clarity of their roles, responsibilities and accountability; an easy read version of the constitution, approved by all board members; clarification of the status of full membership (removing other forms of disability); enabling associate members, generally long-standing relationships to Our Voice SA to have input into the decision-making process without dominating or overtaking the board discussions or decisions (e.g., asking permission to speak at the meetings).

The Our Voice SA staff observed growth of the board over time in engaging with information, taking greater ownership and responsibility for roles, by all members of

the board, demonstrating a stronger voice. Examples of this included members asking more complex questions, persisting with questions to get satisfactory answers, and seeking additional information when presented with the finances.

The board members and staff reported that the quality and readability of easy read information and documents had improved since the start of the project. One example was the budget information, “The numbers and words are now presented with a colour chart, which makes it much easier to understand” (Our Voice SA board member and peer mentor).

The Our Voice SA project team reported the new processes they developed and improve how information was presented, assisted members in their decision making. Some of the processes included training for board members and consulting with specialist accounting skills at Purple Orange to develop more accessible reporting mechanisms which still complied with legal requirements. A regular review process was used, known as the Path Process, which mapped clearly what has been achieved, and where the project was heading. Strong project leadership and facilitation skills by the team, combined with improvements to easy read information and the use of other processes, boosted the boards capability and capacity to self-govern Our Voice SA.

4 Challenges and opportunities for self-advocacy

The Our Voice SA project, its members and the self-advocacy group as a whole, have grown over the last two years. Outcomes and connections have resulted from the growth in members' confidence and skills, changes to staff, the range of strategies to build individual and group advocacy skills and leadership and relationship building have resulted.

Challenges and barriers persist for people with intellectual disability linking with peers, taking on leadership, having a voice and impact in the places they live, work and public life.

4.1 Sustainability of peer support

It took considerable effort – investment of resources, time and persistence – to establish relationships, networks and reach into regional areas and some closed systems.

Four factors that enhanced sustainable groups were building relationships in the group, involvement of peer mentors in group facilitation and activities, partnering with an organisation to host peer groups and activities; and ongoing, skilled facilitators to organise and run the groups.

Many of the regional and metro peer groups grew well in the number and attendance of participants, attendance at other groups declined over time. Few and inconsistent participation also negatively affected the remaining participants and group dynamics.

Multiple reasons explained the experience of declining and fluctuating attendance. Reasons were:

- **structural** – limited funding or support to attend, capacity to attend reliant on support workers shifts and availability, lack of transportation or suitable community venues in regions, not seeing an impact of change in the organisation from the feedback provided
- **environmental** – belief that there is 'nothing on' in the regions, finding a suitable time that works for everyone, changes in group attendance
- **personal** – preference for different activities, limited confidence, discomfort for some in sharing in small groups with people they did not know well

Opportunities

Future considerations to sustain the peer support groups could include:

- Continue the approach of investing in partnerships with organisations that have an interest in and support for capacity building work.
- Review peer mentor positions and roles and identify how to extend this resource. Suggestions include facilitator training and development opportunities to peer mentors, so they can take on greater leadership in the activities
- Seek feedback from participants about attracting new and diverse participants to the peer groups in supported accommodation settings. Questions include how to improve knowledge about the groups, share stories about the impact and types of activities, offer support to attend and remove other perceived barriers.
- Continue to explore new forms of engagement and connection for people, expand activities, such as creative or art-based workshops to enable people to express their voice and ideas through different mediums.
- Consider partnerships with organisations working with related communities (e.g., multicultural communities, children and young people, First Nations communities) to extend reach into people with intersectional experiences.

4.2 Organisational culture and accountability

Participants in some peer support groups and activities in closed systems started to see changes in their work and living environment, relationships and interactions with other people. The changes were in policies, practices and expectations towards people with disability. Other groups remained in the early stages, with little or no impact. The mixed outcome from peer activities is unsurprising, considering the long history of some organisations.

It was difficult to establish new engagement with some organisations (closed systems), where Our Voice SA had no existing relationships, limited trust and understanding of their approach, organisational culture and gatekeeping (fears, biases, limited understanding of the benefits of self-advocacy).

The capacity to engage with organisations was affected by the culture of organisations. The culture facilitated or constrained what was possible in the groups and development activities, and the impact of self-advocacy more broadly. Examples of organisational culture factors included: the topics and issues acted on or declined

by management; layers of approval; who receives easy read meeting minutes (only members or broadly shared with residents); and who was present when the peer group identified issues are shared with board and management.

The peer network groups and activities within organisations appeared to be most effective when people with intellectual disability and Our Voice SA staff had alliances with senior decision makers. A key ally in management was central to leveraging their position with the organisation to influence culture and administrative processes. Management and staff turnover restricted the impact of the work in some closed systems and established organisations.

Opportunities

Our Voice SA could consider implementing additional accountability measures to sustain the impact of peer activities in closed systems and services,

- Easy read materials (minutes) need to include detail about actions required to respond to change requested. People find it hard to remember and it makes it difficult to hold management accountable.
- Ensure representation of alliances including Our Voice staff at management/board meetings to present key issues identified by the peer groups to enhance accountability and responsiveness
- Schedule regular reviews (e.g., 6-monthly) of identified actions and progress on remedial actions (how, when, and what items are being addressed or not)
- Circulate actions and progress by the peer groups with a broader population of people affected by the changes or lack of change
- Consider management development training on best practice on respectful communication with groups to enhance their engagement with its self-advocacy groups.

4.3 Future sustainability of self-advocacy

Self-advocacy by and for people with intellectual disability requires resources: suitable venues (places and spaces, technology) to meet; paid staff to facilitate, coordinate and organise; administration (HR and payroll support) for staffing; funding to support members to attend local meetings, state and interstate systemic advocacy events; delivery of conferences and capacity building activities; building of partnerships and relationships; investment in the leadership by peer mentors and other members.

Our Voice SA developed during a particular period. The introduction of the NDIS meant the organisation has received ILC grants to expand their reach, diversify their activities and develop their profile in the broader community, while building individual and group members' confidence and self-advocacy skills.

Funding security is a major concern for the organisation, with implications for the direction of current activities and strategic planning for the future. The Our Voice SA board have sought a range of avenues to increase financial independence, including registration as a charitable organisation, seeking payment for consultations, and increasing self-reliance of some more established peer group activities. However, core funding remains a central concern to ensure the group continues to exist.

Opportunities

Our Voice SA has built expertise, experience and connections as a self-advocacy group that can continue to extend its impact to other people with intellectual disability. Future considerations for development include:

- Use established good practice and members' capacity to extend into innovative areas of work. Examples include, demonstrating board leadership in meaningful, inclusive governance models; and peer mentors taking greater leadership roles.

- Find ways of attracting diverse membership – young members, culturally diverse, regional, Indigenous people. Encourage and support new members in peer mentoring and roles on the board and other governance activities.

- Link activities to maintain a sense of connection and impact of the group beyond the smaller peer activities. Examples include links between members in metro and regional groups through activities and events.

- Focus some resources on work that requires development. Examples include groups or locations that remain unstable or have potential for greater impact. Consider how to shift resources from intensive activities where the group has already made significant change or where other funding sources might be available, for example, review less relevant, unpaid, or resource intensive consultations.

- Linking and collaborating with self-advocacy groups in other states to learn,share and maintain "strength in numbers".

The research demonstrated that Our Voice SA's Reaching Out project achieved impact and outcomes for people with intellectual disability in South Australia. The benefits included connections with peers, improving practice, building leadership

capacity, and being heard and listened to by people in decision making positions. The program also manages persistent barriers and challenges faced by people with intellectual disability. The capacity of the members, development of relationships and connections requires continued organisational support to extend the impact of the peer support approach. The community faces the risk of losing that peer support and self-advocacy capacity if ongoing funding sources are not secured.

Appendix A: Research 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.

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.

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, including the Personal Growth Index Scale (PGIS) survey data (2021-22).

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 six people with intellectual disability and four 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.

Part of the Our Voice SA program data is the Personal Growth Initiative Scale (PGIS) (Robitschek, 1998). The survey was administered by the project staff before and after some, not all, delivered capacity building workshops. The survey measure changes in participants' self-assessed advocacy skills, confidence, and knowledge.

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 and authored named contributed to writing this report.

Appendix B: Our Voice SA numbers

Table 2: Project Data for 2021-2022*

2022 Peer Networks		
	No. of meetings	People attending
Our Voice SA	10	69
Provider 1	10	37
Provider 2	10	57
Region 1	9	13
Region 2	7	7
Region 3a	10	43
Region 3b	10	38
Region G1	9	94
Region F2	14	81
Region F3	8	97
Region H1	6	62

2021 Peer 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

Our Voice SA Board Meetings		
2021	10	40
2022	10	71

2022 Capacity Building Workshops		
Provider 4	5	16
Region G1	10	16
Region F2	6	39
Region F3	5	11
Region H1	7	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

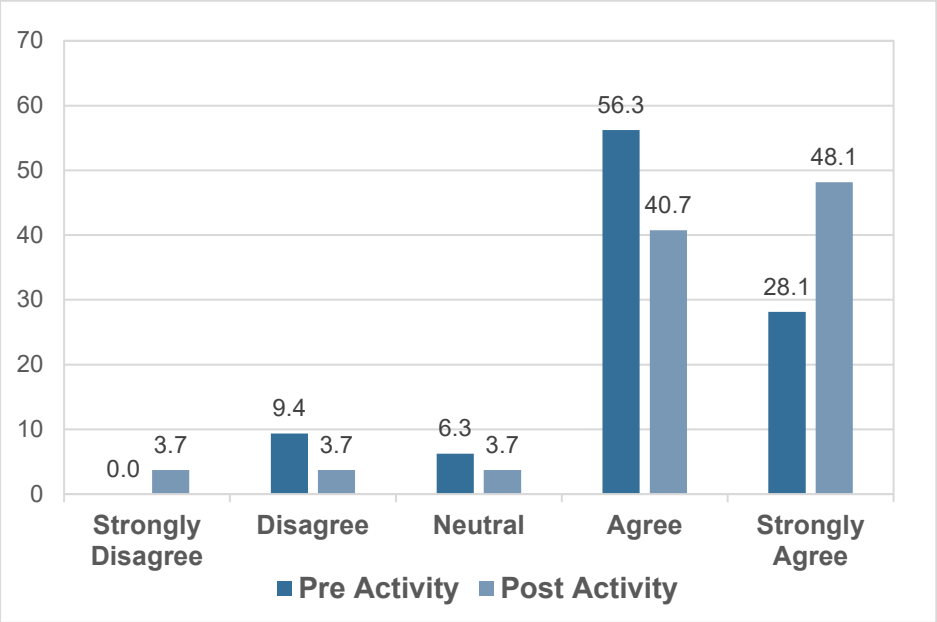
2021-2022 Consultations		
Focus Groups	11	44
IDPWD	3	27
NDIS	1	11
Restrictive Practices		4
PO Strategic Planning		5
SA government		4
DRC		1
University advisory 1		4
University advisory 2		4
Business consultancy		3
DRC		2
IDPWD 2021		3

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

*Anonymised for confidentiality

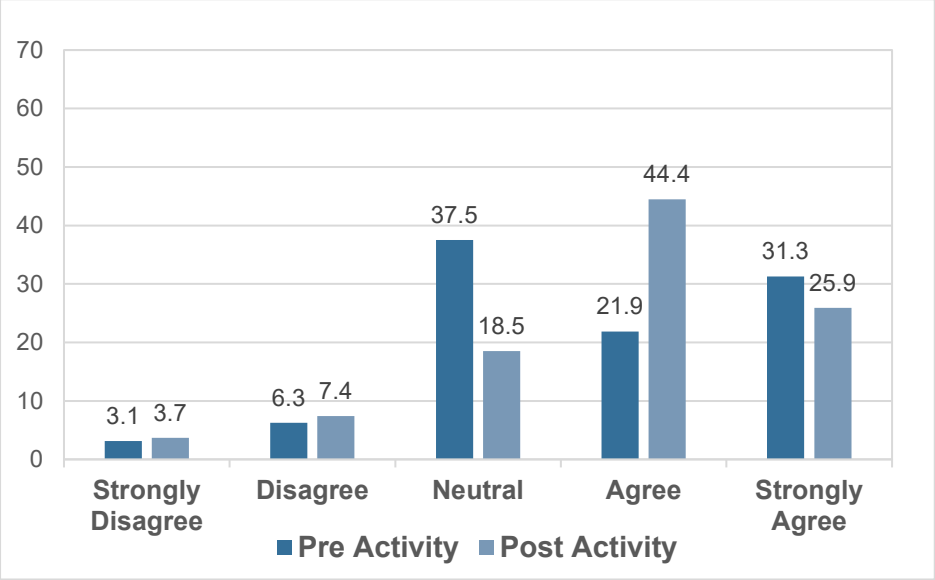
Personal Growth Initiative Scale, 32 (n) pre-workshop activity and 27 (n) post-workshop activity

I know how to change things in my life if I want to (per cent)



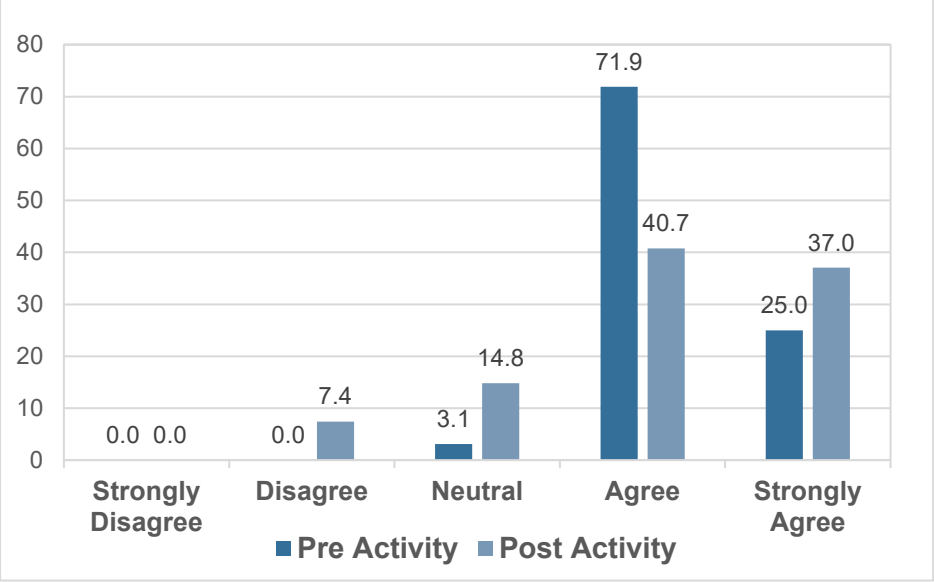
Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)

I have a plan about my future (per cent)



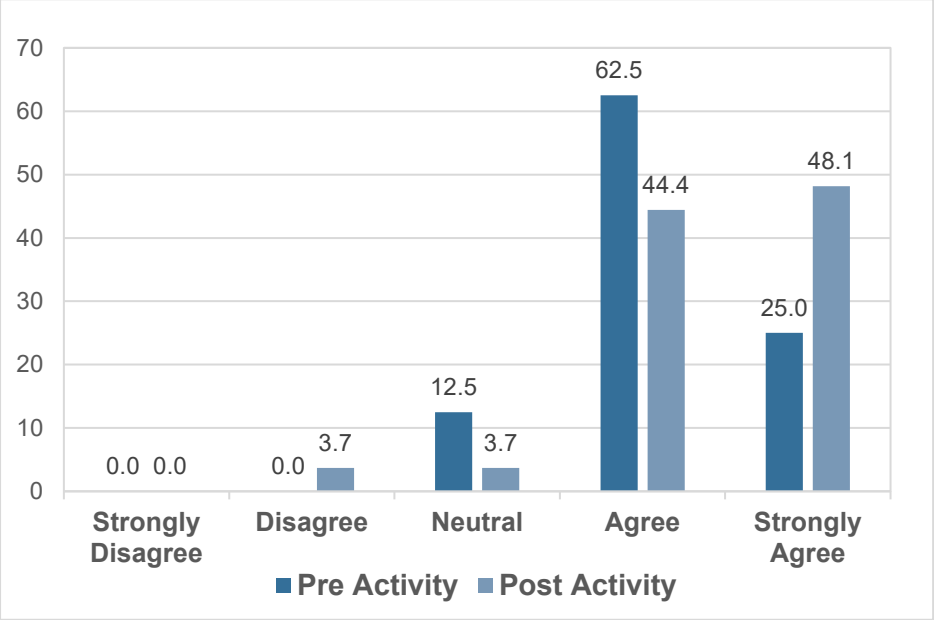
Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)

If I want to make a change I can, to help me make decisions (per cent)



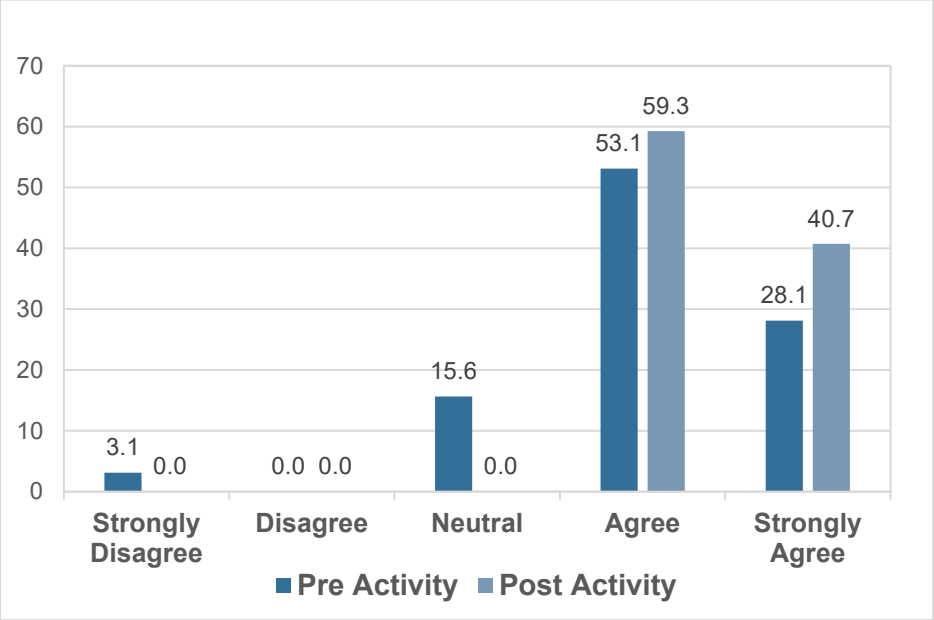
Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)

I can choose what groups I go to and what I do there (per cent)



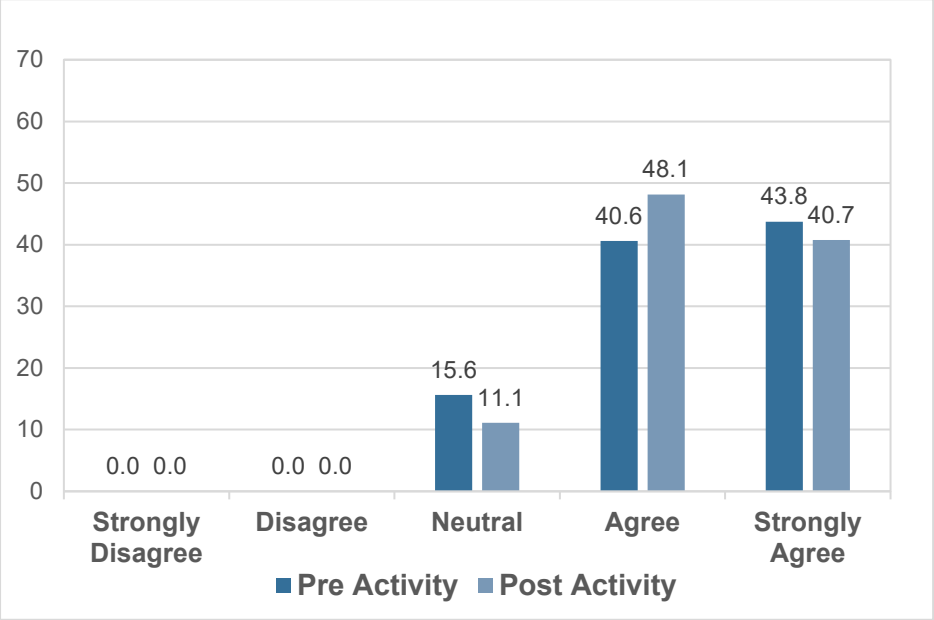
Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)

I am in charge of my life (per cent)



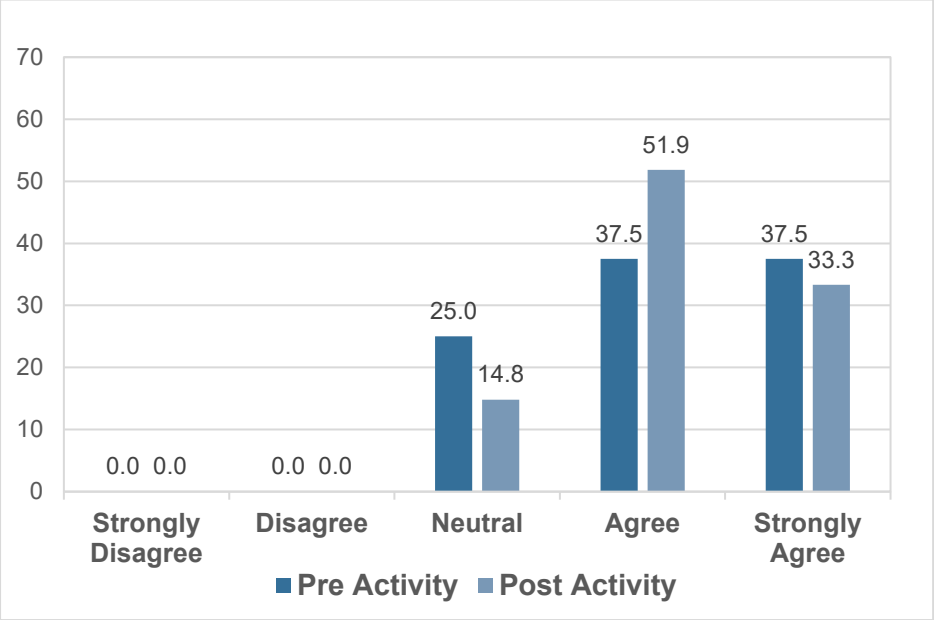
Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)

I feel good about who I am (per cent)



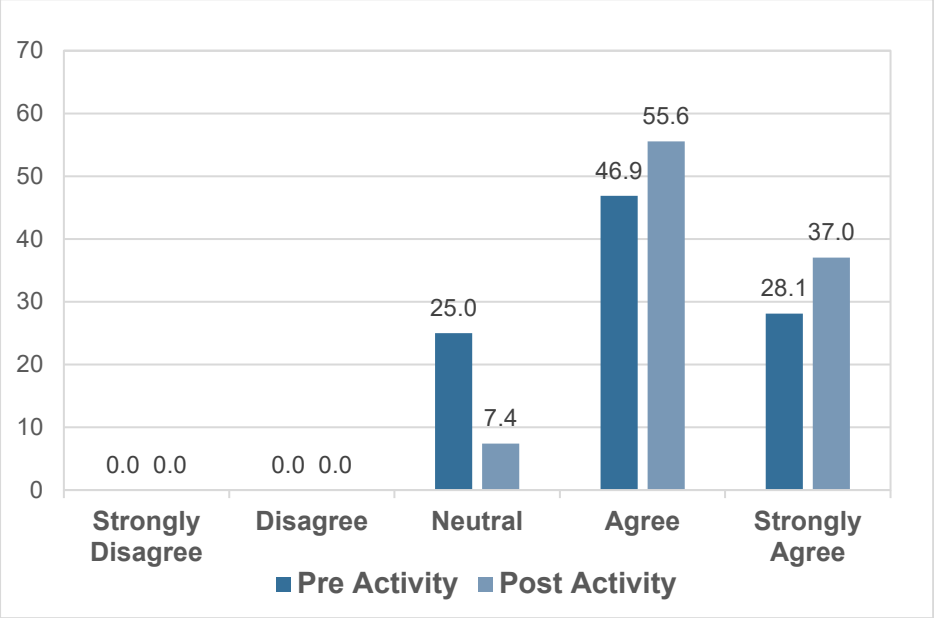
Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)

I feel good about my future (per cent)



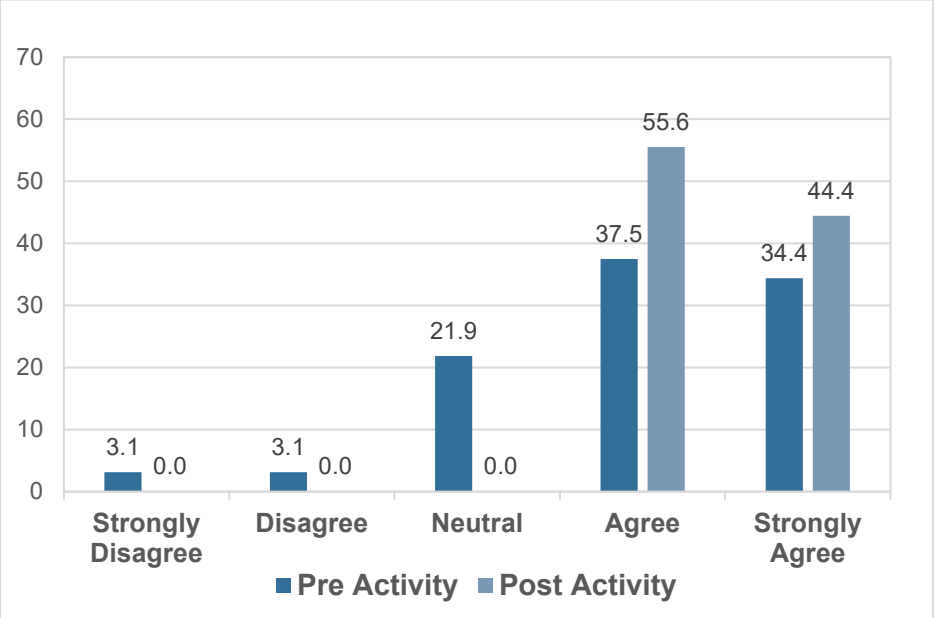
Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)

I choose what to do everyday (per cent)



Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)

I choose where I live and who I live with (per cent)



Source: 2021-22, Personal Growth Initiative Scale (PGIS) (Robitschek, 1998)