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National Alliance of Capacity- building Organisations (NACBO)

Final Evaluation Report

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Flinders
University

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Glossary

Alliance	NACBO
Ally	Friend, colleague, neighbour (an ally commonly is an unpaid supporter, in rare cases they can be a paid supporter).
Business, job mentor	Member of the community or a professional with relevant industry experience
CALD	Culturally and linguistically diverse
Customising work	Customised employment is a person-centred approach to employment supports and services. The approach tailors a job to fit the skills, interests, strengths and support needs of a person with disability whilst meeting the needs of business.
Disability Royal Commission	Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
DSS	Department of Social Services
Family	Person with disability, parents, siblings, grandparents, extended family and other people considered family members
Flinders University	Evaluation team
ILC	Information Linkage and Capacity-building funding program
NACBO	National Alliance of Capacity-building Organisations
NACBO members	Belonging Matters, Victoria Community Resource Unit (CRU), Queensland The Institute for Family Advocacy and Leadership Development - trading name - Family Advocacy, NSW Imagine More, ACT JFA Purple Orange, South Australia Valued Lives Foundation, Western Australia
NACBO leaders	Focus group with NACBO leaders from the 6 members
NACBO organisation	One of the NACBO members, name removed for person's privacy
Person, people	Person, people with disability
SPRC	Social Policy Research Centre, UNSW evaluation team
UNSW	University of New South Wales Sydney

Short Summary

NACBO is a national network of six organisations. They provide a range of capacity-building activities and resources, driven by principles of social and economic inclusion, to empower people with disability, with the support of their families and allies, to live a fully included life and participate in their communities. This means having the same opportunities and pathways as other citizens. Capacity-building is delivered through three major methods of delivery or processes: 1. Information and learning and raising expectations, 2. Individualised follow up and mentoring with peers and 3. Leadership development for people with disability and their families.

NACBO process, impact and outcomes

The evaluation found that the principles and capacity-building processes used by NACBO changed outcomes for people with disability and promoted authentic inclusion. Raising expectations about inclusive lives and addressing ableist assumptions about service use changed people's lives.

People with disability experienced positive outcomes across a broad range of life domains. Outcomes in one area of life were often connected to outcomes in other areas, creating a more holistic impact and good life in the community. Where people with disability and families connected with NACBO, outcomes were achieved in five main areas:

1. Educational inclusion outcomes
2. Greater say, self-direction and leadership in daily life
3. Connections, belonging and community, own home
4. Economic and social contributions
5. Planning and safeguarding for the future

People gained self-direction and a sense of belonging in their community. By focusing on valued roles, people were known, had connections and contributed both socially and economically to their communities e.g. attending a mainstream school, finding and keeping employment, living in their own home (of their own choice); and taking leadership in their daily lives.

Information, learning opportunities and resources often triggered an idea or changed people's mindsets as to what was possible. Follow up activities (such as personalised conversations, mentoring and building networks of peers) helped people to apply the capacity-building in their own lives. People applied what they learned from the broad capacity-building activities and used personalised assistance to relate it to their own lives.

Increased confidence, personal growth were also key outcomes from involvement in NACBO's capacity-building. NACBO intentionally invests in people and their families to equip and support them to take on leadership roles e.g., sharing their story, advocacy, governance, lobbying, and various facilitation, employment or volunteer **roles**. This leadership helped raise the expectations of their peers and others by grounding capacity-building in lived experience.

Capacity-building was not a once off activity for most people. Achieving and sustaining long term outcomes required capacity-building at major life transition points e.g., starting and leaving school; transitioning to work, leaving a day program to find paid employment, moving out of the family home or a group home.

Elements of effective capacity-building for future government policy and organisational practices

1. **Principles.** The principles and rights to authentic inclusion in the community are embedded in the processes and life outcomes of capacity-building.
2. **Person at the centre.** Capacity-building prioritises the person's motivations and preferences, understanding their changing situation, interests **and** goals.
3. **Across the life course.** Capacity-building is a lifelong process. It takes time to address new goals and overcome challenges that change over a lifetime. People choose from a range of capacity-building options according to what is most useful at the time.
4. **Holistic and interconnected.** Capacity-building equips the person and their networks of support (families, allies and friends) to lead change according to the person's preferences. Information and resources are linked to activity that builds high expectations, follow up, leadership opportunities and networks of peers.
5. **Leadership.** Investing in intentional leadership of people with disability and families can have an impact on personal and community development, as well as peer learning and sustainability. Effective leadership can also drive positive change in systems and policies.
6. **Long term outcomes.** Achieving success in capacity-building requires taking incremental steps towards long-term outcomes. Maintaining ongoing connections with capacity-building organisations and networks is important in order to meet high expectations.

Executive summary

NACBO is a network of six organisations. They provide a range of capacity-building activities and resources, driven by principles grounded in social and economic inclusion, to empower people with disability, with the support of their families and allies, to live a fully included life and participate as equal members in their communities. Capacity-building is delivered through three major methods of delivery or processes: 1. Information, learning and raising expectations, 2. Individualised follow up and mentoring with peers and 3. Leadership development for people with disability and their families.

NACBO asked researchers at two Australian universities to undertake a two-year evaluation of the NACBO capacity-building model. The research aimed to understand the strengths of the NACBO model and implications to improve capacity-building policy. The National Disability Insurance Scheme (NDIS), Australia's Disability Strategy (ADS) and other change initiatives funded by the government, rely on capacity-building to fulfil the rights and achieve outcomes for people with disability. These policies are intended to form an inclusive society and sustainable disability support system.

NACBO process

The NACBO approach to capacity-building is to implement and integrate three processes. These are learning, follow-up and leadership development. They aim to build high expectations that lead to social and economic contribution, leadership and control for people with disability and their families. Capacity-building activities are driven by clear principles focused on social and economic inclusion. The model included individually tailored approaches to keep the person at the centre, in the context of their family.

The evaluation found that the principled capacity-building processes used by NACBO, directly and indirectly, changed mindsets and outcomes for people with disability in regard to authentic inclusion. It also raised expectations and changed lives by empowering people with disability and families.

People and families engaged in a variety of learning opportunities e.g., workshops, resources and information drawn from evidence-based frameworks and illustrated with stories of what is possible. Stories from peers raised expectations by showing what was possible. Follow up activities included personalised conversations, mentoring, networks of supporters and peers. This assisted people and families to think about their own lives and create change.

To create and sustain change, NACBO encouraged people and families to take on leadership as they gained skills and experience. Leadership roles were within and

outside NACBO organisations. NACBO offered a range of paid and voluntary leadership roles for people and families. This investment in leadership contributed to personal growth and raised expectations for other people with disability and families.

NACBO capacity-building empowered people with disability and families by increasing skills, knowledge and confidence to make changes in life. The approach shifted their expectations and mindsets. “Seeing is believing, you have to see it, to believe it” (person with disability employed by a NACBO organisation).

Holding higher expectations, seeking out and creating tailored opportunities for people with disability to live a good life were starting points to change and sustained outcomes for people with disability.

NACBO impact and outcomes

Where people with disability and families connected with NACBO, outcomes were achieved in five main life areas:

1. Educational inclusion outcomes
2. Greater say, self-direction and leadership in daily life
3. Connections, belonging and community, own home
4. Economic and social contributions
5. Planning and safeguarding for the future

People with disability connected to NACBO capacity-building started in mainstream education or changed schools, rather than attending specialised disability education.

Having greater say about the direction of their life was central to how people with disability gained leadership in their daily life. They built their capacity in many ways: through practice alongside their families, coaching from NACBO staff, attending capacity-building events, working in small groups with peers and learning from each other.

A central outcome from the NACBO capacity-building approach was people with disability and their families feeling more connected to their local communities and the people around them. Outcomes from capacity-building included identifying and developing social connections; and intentionally investing in and forming new connections and relationships with people in the local neighbourhood.

A long-term outcome of NACBO’s approach to capacity-building was choice about where and with whom to live. Depending on their age, people with disability, with the support of families and allies, were exploring ways to live in the community, taking

the time to find out what they wanted and taking the steps to make it happen. Other people had already achieved various ways to live in their own home. Some people were supported to leave congregate living and disability employment.

People gained a range of socio-economic and educational outcomes and found personalised, meaningful ways to contribute to their communities as a result of their connection to NACBO capacity-building. Many people contributed in more than one way. They also took on leadership, directly and indirectly influencing the places, practices and people they worked with, and the community more broadly.

People with disability and families planned for the time post school, when many structures and social connections change for all young people. Planning for work and employment began for many while young people were still at school or had just left. Creating a network of people who genuinely care to uphold a person's interests and preferences was considered a first major step to safeguarding a good life.

NACBO collaboration

Although connected informally for many years, the six like-minded organisations decided to formally collaborate and formed NACBO in 2015. This provided the opportunity to share knowledge and strengthen a broad voice of people with disability and families, to influence system and policy change in regard to social and economic inclusion. It also offered a community of practice to explore issues, garner support and provide further leadership opportunities for people with disability and families to influence change at a national level.

All NACBO organisations depend on government grants to sustain their capacity-building activities. Uncertainty of funding and short-term grants, constrain the work of NACBO and its ability to support people with disability and families to influence system change and more importantly, empower people with disability to pursue valued roles and contribute to the social and economic fabric of their communities.

Opportunities for capacity-building

If capacity-building is firmly embedded in government policy, as a significant method to create change, NACBO organisations are well positioned to respond to new opportunities for capacity-building.

People with lived experience leading capacity-building with their peers

NACBO is committed to encouraging and developing the leadership of people with disability and families as agents of change through strategically building people's skills. Further investment in capacity-building is likely to extend this approach to position more people with disability in leading the design, implementation and

evaluation of future capacity-building, including influencing policy and system change.

Capacity-building with diverse participants

NACBO organisations vary in the degree to which they have resourced participants from diverse backgrounds and rural and remote areas. Strategies depended on their history, size and resources to address such needs. Future consideration could include seeking resources for opportunities to prioritise inclusion of under-represented groups.

Elements of effective capacity-building for future government policy and organisational practices

1. **Principles.** The principles and rights to authentic inclusion in the community are embedded in the processes and life outcomes of capacity-building.
2. **Person at the centre.** Capacity-building prioritises the person's motivations and preferences, understanding their changing situation, interests and goals.
3. **Across the life course.** Capacity-building is a lifelong process. It takes time to address new goals and overcome challenges that change over a lifetime. People choose from a range of capacity-building options according to what is most useful at the time.
4. **Holistic and interconnected.** Capacity-building involves the person and their networks of support (families, allies and friends) to lead change according to the person's preferences. Information and resources are linked to activity that builds high expectations, follow up, leadership opportunities and networks of peers.
5. **Leadership.** Investing in intentional leadership of people with disability and families can have an impact on personal and community development, as well as peer learning and sustainability. Effective leadership can also drive positive change in systems and policies.
6. **Long term outcomes.** Achieving success in capacity-building requires taking incremental steps towards long-term outcomes. Maintaining ongoing connections with capacity-building organisations and networks is important to meet high expectations.

1. Introduction

National Alliance of Capacity-building Organisations (NACBO) is a network of six organisations across Australia. They work with people with disability, their families and allies to build capacity for people to live a full and included life and participate as valued members of mainstream communities.

NACBO asked researchers at two Australian universities to undertake a two-year evaluation of the NACBO capacity-building model. The research aims to understand the strengths of the model and implications to improve capacity-building.

1.1 What is capacity-building?

Capacity-building is a process by which people, groups or organisations develop their capacity (individually and collectively) to perform functions, solve problems, set and achieve goals, understand and deal with their needs in a broader context (Independent Advisory Council, 2015). In the context of disability, capacity-building has been an important transformation, moving away from deficit-based thinking, where ‘experts fix problems’, to a strength and partnership based approach, where people with disability, their family members, friends and formal supporters work together. Importantly, this shift allows ‘decision making power to rest with those whose capacity is to be developed’, professionals (or capacity builders) may take on the role of problem analyser, solution designer or facilitators (Independent Advisory Council, 2015, p. 9).

Another key underpinning of capacity-building is that it acknowledges that the process takes place ‘over time requiring a multitude of strategies and activities at the individual, community, organisational and systemic level to be sustainable’.

Capacity-building ‘will be most potent when multiple level strategies address the complexity of barriers in people’s lives’ (Independent Advisory Council, 2015, p. 9).

In the context of the NDIS, individual capacity-building has been identified as critical for people with disability, their families and support networks, as it enhances knowledge, skills and has the potential to bring about personal change and also contribute to broader change. Capacity-building in the context of the NDIS focuses on health and wellbeing and empowerment of people, to build a good life for the person. It is also directly relevant to the sustainability of the NDIS, which in part is dependent on people with disability being engaged in social, economic and civic life (Independent Advisory Council, 2015, p. 11).

How NACBO builds capacity

NACBO organisations strategically came together due to their shared vision and deeply held principles that people with disability should be afforded the good things in life and that these things are often only attained through authentic social inclusion.

‘The good life’ is also a foundational aspect of the purpose of the NDIS. This aspect of NDIS often does not translate into people with disability asserting more ‘choice’ and ‘empowerment’ in their day to day lives.

NACBO vision

A rich, strong network of capacity building organisations that assist Australians with disability without exception, to belong, participate and contribute through typical and valued roles within their local community.

NACBO purpose

We are a strong national alliance working together to equip people with disability and their families locally to address the systemic and deep-seated barriers they face. We do this through an aligned, evidence-based capacity building approach.

We create impact through influencing, sharing knowledge, creating resources, developing leadership and delivering joint projects on social and economic participation.

This means transformational, values based local capacity building organisations are available for Australians with disability and their families.

NACBO believes that the typical and ordinary spaces and opportunities that most Australians enjoy are often not afforded to people with disability. The organisations recognise that this stems from the social devaluation of this group that distances people with disability and which plays out in historical approaches such as institutional structures and practices and more recently in segregated disability-specific programs that continue to congregate people with disability and keep people at arm’s length from their communities.

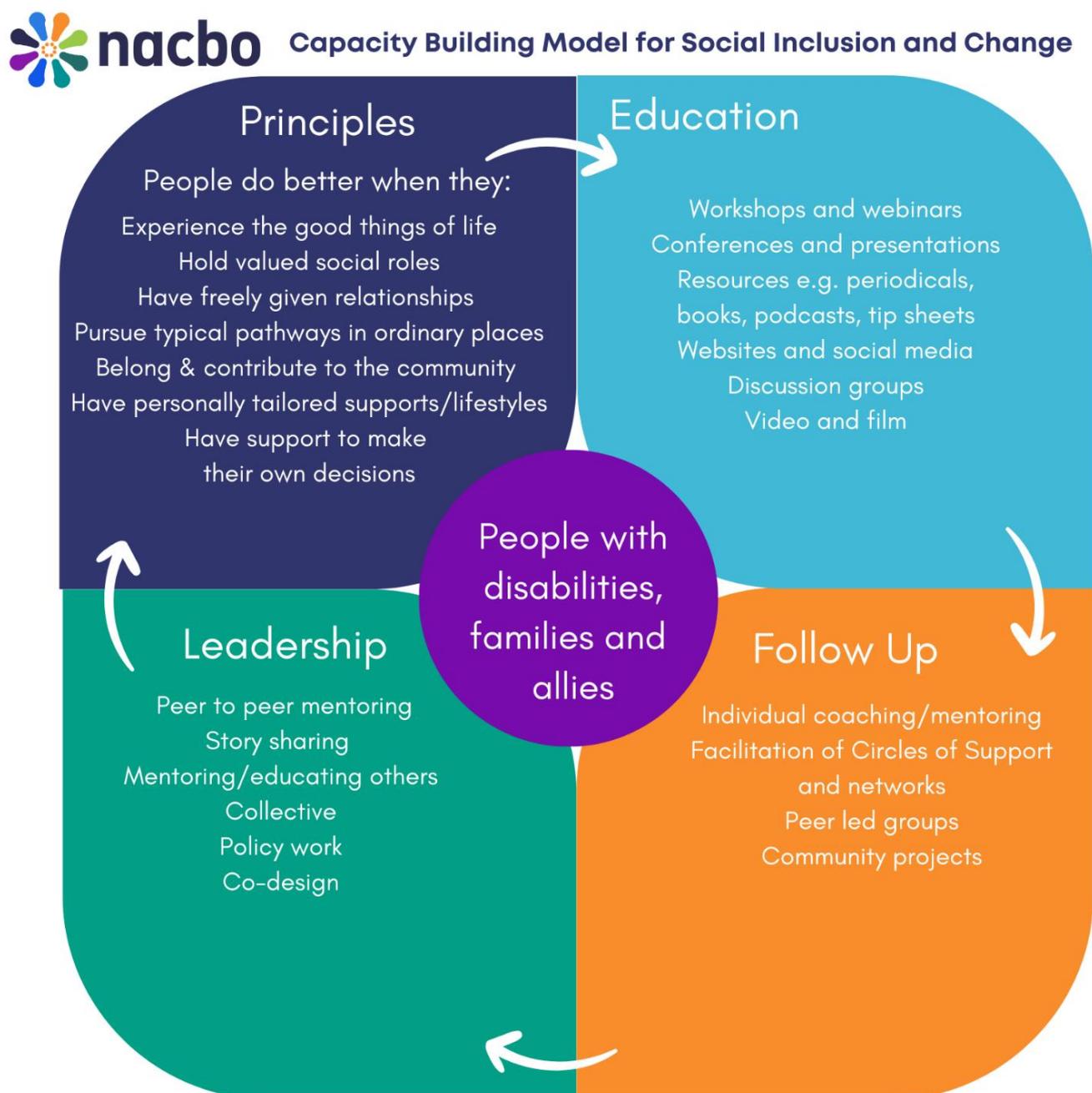
Each NACBO organisation has been guided by Social Role Valorisation theory (Wolfensberger, 2013; Kendrick 2011; Kendrick et al 2017) or, in the case of one organisation, the Model of Citizenship Support (Williams 2013). NACBO organisations use the framework to support people to develop their capacity to counteract the devaluation of people with disability. In simple terms SRV theory purports that the more roles a person has, and the more valued the roles are, the more likely they have the good things in life. Using the lens of roles, these organisations assist people with disability and their families to cut through the web of

institutionalised thinking and focus on developing and strengthening roles that are typical, aligned with the person's stage of life and interests and of the highest social value. NACBO identifies that this creates a means for people with disability to identify and connect with other members of the broader community through various shared roles and contributions (and vice versa) and acts as a safeguard against potential further harm. It also enables typical learning opportunities and environments to be shared with one's non-disabled peers. For many people with disability their key life role is that of dependent service recipient/client and this in fact further isolates them from their community.

NACBO works to build the capacity of people with disability and in recognition of these barriers in regard to accessing the good things in life, they also prioritise the development of family members and allies. Families are typically well placed to support their family members to achieve the good things in life and this can at times be required over the lifetime of the person. Families are also in a position to influence the early pathways of their loved one such as access to an inclusive education. Families often have the greatest interest, know the person best and are well positioned to push back against low expectations, limited opportunities and harmful practices. They are also likely to have the biggest influence over the person's life course.

Figure 1.1 summarises the NACBO capacity model. More details are in Section 2 and Appendix 1. Not all NACBO organisations implement all parts of the model.

Figure 1.1: NACBO capacity-building model



1.2 What is NACBO

The National Alliance of Capacity-building Organisations (NACBO, the Alliance) is a network of six not-for-profit organisations. The six independent organisations all receive government funding and have operated for many years.

The 6 NACBO organisations have a history of mutually sharing information, practice, and resources related to capacity-building, and in the context of a deep and shared

commitment to people living with disability having valued, contributory roles that bring sustained membership and belonging in mainstream community life.

In 2015, the organisations resolved to meet on a more regular and intentional basis, and this marked the emergence of NACBO. This created momentum that resulted in attracting funding for several collaborative projects covering themes such as self-managed supports, employment and the nature of home. The NACBO members collectively and separately operate projects funded from the Information, Linkages and Capacity-building (ILC) program.

The six NACBO organisations are:

- Belonging Matters (VIC)
- Community Resource Unit (CRU) (QLD)
- Imagine More (ACT)
- Family Advocacy (NSW)
- JFA Purple Orange (SA)
- Valued Lives Foundation (WA).

The mission of NACBO and its members is to promote the position of people with disability as valued, contributing citizens and build competencies, skills and connection of people and their family members within the community. The ultimate objective is to empower people and families, so people with disability are guided and supported to take up valued roles through opportunities that lead to meaningful lives, embedded in their local communities.

NACBO has developed a capacity-building model for its activities (Figure 1.1). The model is a principled, multi-strategy approach that aims to shift deficit-based thinking, where 'experts fix problems', to strengthening the capacity and vision of people and their families in regard to inclusion. Through such capacity-building opportunities people, with the support of their families and allies build and progress a vision for an inclusive life in the broader community, beyond services.

The principles of the model aim to address the problem that people with disability often are devalued in society, face social barriers and low expectations from the broader community. Through a multi-strategy approach of capacity-building activities, embedded in principles of social inclusion and valued roles, people with disability are more likely to be aware of what is possible and create their unique journey to achieve full, meaningful lives that are embedded in their local

communities, have typical social roles, and opportunities to develop and demonstrate leadership.

NACBO has more than 80 years of combined experience shifting mindsets. Prior to NDIS, most NACBO organisations received funding from their State Government departments. In 2020-2021, NACBO members received funding through ILC. The Department of Social Services (DSS) now manages ILC. ILC projects are to build the capacity of people with disability and their families to enable fuller social and economic participation of people with disability.

1.3 Scope of this evaluation

NACBO commissioned the Social Policy Research Centre (SPRC) UNSW Sydney and Flinders University Adelaide to undertake a two-year evaluation of the NACBO capacity-building model.

The purpose of the evaluation was to review the NACBO capacity-building model of change and examine how it empowers people with disability and their family members to build knowledge, competencies, develop leadership and for people with disability to lead valued and included lives.

The evaluation was not limited to the funding NACBO organisations received through ILC. The research covered a range of capacity-building activities, but not all activities of the six NACBO organisations. The analysis presented in the report is about the NACBO capacity-building model, and examined different activities and processes used by NACBO organisations as evidence about the model. The analysis did not evaluate each of the six member organisations in their entirety.

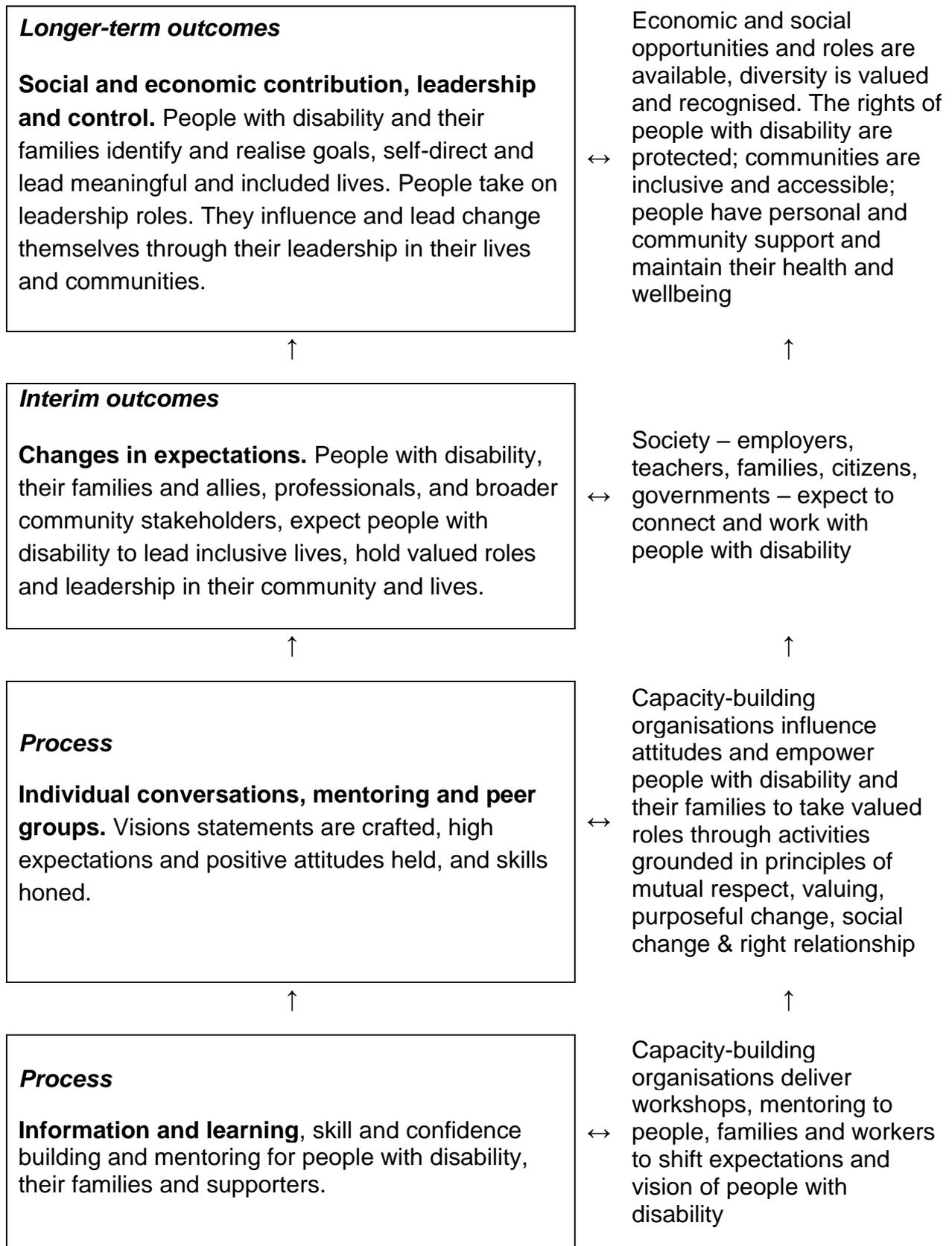
Research outputs from this study will be available on the [evaluation website](#) at the SPRC, UNSW.

The report is structured according to the evaluation questions about impact, effectiveness and lessons (Appendix E).

The NACBO program logic illustrates how the NACBO model envisions social changes, social and economic contribution and valued lives for people with disability with and through their families (Figure 1.2). The evaluation was designed to capture that change.

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

Figure 1.2: NACBO program logic



2 NACBO capacity-building model

The NACBO capacity-building model (Figure 1.1) consists of three integrated processes, driven by a set of principles to enable fuller social inclusion, valued roles and individual and family leadership.

1. **Information and learning**: this includes multi-strategy learning opportunities e.g., workshops, conferences, videos, publications and tailored information on a range of topics; raising expectations of people with disability and creating a vision for a good and full life in the community; building competencies, skills and confidence of people, family members and allies supporting a person.
2. **Follow up and mentoring**: individual conversations and mentoring; learning from others in peer groups; facilitation of groups of informal supporters working together to empower a person with disability and protect their rights (Discovery Meetings, Circles of Support); connection and sharing with peers; community projects.
3. **Leadership development and opportunities**: people with disability and their families are resourced and supported to take up leadership roles. This may include presenting and sharing their lived experience stories at peer meetings, conferences and other occasions; educate or mentor others (e.g., in peer groups); provided opportunities to take part in co-design of projects, development of educational content or policies; take on more formal leadership roles (advisory, board membership) and through leadership in their own lives.

The NACBO capacity-building model intends to influence social change and inclusion of people with disability by building knowledge and confidence of people and families, raising expectations, empowering people directly and through resourcing their family members. A central idea underlying the NACBO model is that people with disability and families lead their own change.

Another key feature of the model is that it acknowledges that **capacity-building is an ongoing, at times lifelong, and non-linear process**. People and families may return to educational events and resources at different stages in the persons' life for example, young people leaving school and seeking employment; leaving the family home and moving into their own home; learning how to self-direct; safeguarding the future and other key transition points.

People with disability and their families use one or more of the educational events and resources, depending on their current information needs, interests, stage of life, goals and other factors. Once people engage with the content and information they may follow up, seeking tailored advice to help them implement their plans from a NACBO organisation or seek support and guidance elsewhere. Tailored mentoring and strategies are often crucial to help people and families make the changes they want to see in the person's life.

Leadership by people with disability and families occurs as they acquire competencies, confidence and influence change, through the leadership in their lives and communities. People with disability may feel empowered to self-direct their life and make decisions that affect them, share their stories with peers and others. When given support and opportunities to lead, people with disability and families may choose to take on different leadership roles such as sharing their story of what is possible, starting a business, civic roles and board memberships, having a say in projects through co-design or policy work.

The model reflects the outcome and policy action areas outlined by Australia's Disability Strategy 2021-2031, which promote:

- Inclusive and accessible communities
- Rights protection
- Justice and legislation
- Economic security
- Personal and community supports
- Learning and skills development
- Health and wellbeing.

3 Outcomes from capacity-building

The NACBO model of capacity-building had a positive impact on people with disability, their families and others. The sections below summarise how the model changed their outcomes, expectations and lives. Evidence about the outcomes is provided in detail in the appendices to help with readability of the report. Analysis about how the model worked is in Sections 4 and 5.

What outcomes have people with disability, their families and supporters achieved because of being engaged with NACBO? Which outcomes are not achieved and why?

People with disability experienced positive outcomes across a broad range of life domains. Outcomes in one area were often connected to outcomes in other areas, creating a more holistic impact and good life, self-direction and personal wellbeing. Five areas where many people connected to NACBO capacity-building achieved changes and outcomes (Stories of change Appendix C) were:

1. Greater say, self-direction and leadership in daily life
2. Connections, belonging and community, own home
3. Economic and social contributions
4. Educational inclusion outcomes
5. Planning and safeguarding for the future

Outcomes often took time and had steps to be achieved, such as attending the same local school as siblings and neighbours, sustaining ongoing open employment, moving into a home of one's own, or making new friendships. At times they required longer term planning, and repeated capacity-building and follow up consultation with families and people with disability. External inputs to achieve outcomes over time included support through guidance, coaching, paid facilitators or services to customise employment; employers embracing inclusive employment; affordable homes; or sufficient family resources. The next part of the report discusses each of the five outcome areas.

3.1 Educational inclusion outcomes

People with disability connected to NACBO capacity-building started in mainstream education or changed schools, rather than attending specialised disability education. A quarter of the NACBO survey respondents (23.3%) said that the person with

disability had either attended early childhood education or kindergarten, school, or higher post-school education (TAFE, university) as a result of capacity-building (Appendix D. Table 14).

Inclusion in mainstream education from early childhood to adult life-long learning were important ways that people with disability and their families felt belonging and connection to their community and peers, other students, families with young children and young adults with similar study interests and course choices.

Isabelle, a young woman in her mid-20s, who attended TAFE and wanted to study at university to become a social worker, said that taking part in education was crucial to fulfilling her career aspirations. Because of the capacity-building she had received from a NACBO organisation, she felt more confident and knowledgeable about how to self-manage her paid supports while she attended higher education (Section 3.1).

The stories highlighted social inclusion outcomes for people with disability, family members and the family unit. Families benefited from capacity-building and the person's inclusion in mainstream education by developing childhood connections and importantly creating higher expectations of the possibilities post school. This was the case in Liam's story, told by Sarah, his mother.

Inclusive childhood connections

Liam lives in a regional small town. His mother Sarah said that when he was born 13 years ago, all they heard were "negative things". She had not heard a doctor or medical professional speak in a positive light about Liam and his future possibilities.

They were involved with the NACBO organisation over the years, which improved Liam's opportunities, language and connections, as well as the families' sense of belonging to their local school and community.

Sarah, Liam's mother said: My son Liam was born with a disability. We attended [NACBO organisation] events and decided we wanted him to go to a mainstream school together with his two older brothers.

People expect the school community to be accepting of a child with disability. It's just not like that. Prior to having a child with disability, I wasn't assertive. But coming to the [NACBO organisation] events and seeing other family leaders, it has helped me develop my skills of speaking out, being assertive, negotiating ideas.

Liam's school is only 3 minutes away by car. If we had pursued the special school it would have been a 45 minutes car or bus ride. Liam attending the local school means he knows the neighbours' children and they know him.

Liam loves his primary school; he comes out happy and laughing most days. But he cannot tell me if something bad happened, if someone bullied him during the day. I don't worry much, I am confident that if something happened that day, I will hear about it from the other children in the school yard. They are little mouthpieces and I count on them, and the other parents, who will tell me if something happened.

This is because the school community is a place where we belong, and the other families and children know we belong. At school events I hear parents tell me what their children say about Liam, what funny things he did during school. They also know he is more vulnerable, and they look out for him.

Liam attending the local school – it's made a huge difference to our life as a family. If he is unwell or upset, I can easily pick him up. Liam is well known in the community; he plays with the neighbourhood children and is invited to school parties. Liam also does horse riding and swimming with his school mates; he has opportunity to play with them after school. In terms of his disability, communication and speech, therapists will say he is really doing really well, above what they'd expect.

I know that Liam is growing up with a sense of where he is from, where he and his family belong and are known. Our family life, and who we are as a family with a child with a disability, would be very different, if we had not made the choice for Liam to attend his local public school.

Other families said that the person with disability had gained good education along with other social benefits, like being known, the connections and sense of belonging that come with attending a local school or being together in the same school as their friends and siblings (for example, Mandari's story). Family members said that the local school and community had been essential to many other social and economic outcomes people achieved later in life, for example, feeling more confident to apply for work in the local supermarket. Attending the local school meant they knew everyone (Clementine's story of family leadership, Appendix C).

3.2 Greater say, self-direction and leadership in daily life

Having greater say about the direction of their life was central to how people with disability gained leadership in their daily life. People and their families said they had more say about their life from taking part in capacity-building. People built their capacity in many ways: through practice alongside their families, coaching from NACBO staff, attending capacity-building events, working in small groups with peers and learning from each other (for example, Marika and Sammy, Appendix C).

Isabelle shared her story of working with a coach from a NACBO organisation to develop her confidence to speak up, setting boundaries and expectations with support workers and enabling her to focus on and enjoy her TAFE study.

Gaining confidence to speak up

Isabelle took part in one-to-one mentoring, NACBO workshops and other capacity-building activities. She explained that being involved had greatly increased her confidence to speak up for herself, make everyday decisions and take greater leadership in life.

Isabelle said: I am in my 20s and love studying ... I want to become a social worker! I have completed two TAFE courses and want to apply for university in the future. I also manage part of my NDIS package; the other parts are plan managed. I have the backup of people in the background but am now learning how to do it myself.

At first, I felt stressed and anxious, I had to work out how to stay on top of my education and manage the support. At some point, I just couldn't cope anymore. I knew [the NACBO organisation]. I had worked with them in the past. I organised some one-on-one consultations with the organisation. Together we worked on building my skills and my confidence to manage my own supports, the people I employ.

After one session I already felt so much better, more confident. I asked for it to continue. I felt like I had found my voice! One day, during class, I decided to do something that my support worker would not agree with, he responded in a passive aggressive manner. I stood up for myself.

I am gaining in confidence about how to speak up and know when it is my right to do so. It has had a big impact on my self-esteem. I know now, if I can do that, I can do almost anything in life!

Some people connected to NACBO received personalised guidance or coaching. Many people received support to live a more independent and self-directed life because their families had access to NACBO capacity-building. Kevin's mother Mona spoke about how they had "tried a day program", but it had not worked for Kevin. Once the family became involved with NACBO they decided to ensure Kevin had more choice, self-direction and greater say about the things he wanted to do in life. Leaving the day program after a year was the first big step. After a couple of years Kevin had two paid part-time jobs in the community, he took part in community groups, like Zumba and the gym, and was learning to become a swimming coach.

Kevin shared his story of change, about how living a life built around his interests gave him opportunities to take leadership in life, make everyday decisions, sometimes seemingly small, but important. Kevin said that every time he gets to "have more say" he also feels "more confident".

Making everyday decisions

Mona, Kevin's mother: After completing school, Kevin started in a day program. After a year, we found that Kevin's ability to choose what he wanted to do was very limited. There were too many rules set up. None of the activities were about his interests. Most of the other people were older. Kevin was also not permitted to cycle there, due to safety concerns, in case he'd get lost or have an accident on his bike. Together, as a family, we decided to try something different - support Kevin to live a life that's built around his interests and what he likes to do.

Kevin, I love sports, Zumba dancing, and riding my push-bike. Twice a week I go to a local gym and am paid to work there. I work at the reception. I also do other jobs around the gym; I organise the equipment. A favourite part of work is getting there and back. I love cycling, most days I ride on my own. Some days I find new roads or I stop and buy something to bring home. I like having my own money!

Kevin and Mona were learning about supported decision making through NACBO. These were courses designed for families and supporters of a person with disability to help them grow and be more aware how to support people to make decisions for themselves while also taking considered risks. The other workshop Kevin attended was specifically aimed at teaching people with intellectual disability about decision making. Kevin attended the workshop with a support worker, by choice.

Supported decision making

Mona, Kevin's mother: I attended a decision-making workshop only for supporters and parents. Because I help Kevin with his decisions. Kevin has many interests, he is social and kind, he also lives with intellectual disability. I don't always know if what I am supporting him to choose is the right choice. Sometimes ... it's not always easy to hold back your own ideas of how things should go, your expectations for your child. I believe, I know Kevin really well. So, in this workshop I learnt how to sort of let him decide more, rather than put too much of myself in his decisions. It's a tricky one.

This [NACBO organisation] has many good events, podcasts and resources, and I have listened to a few of them many times, over and over! They help me stay focused, on what our role is as Kevin's parents, like little reminders to step back little by little, as Kevin is gaining more experiences and growing in confidence as a young man. Kevin is in his early 20s.

Kevin also attended an online workshop about supported decision making, exclusively for people with intellectual disability. His mentor supported him to come on screen and add a few things. The aim of the workshop was for Kevin to gain skills and knowledge about voicing how he feels, what he wants, and how to say these things. Kevin seems to like his role.

Attending those sorts of meetings, together with his mentor, really gives Kevin opportunity to express himself more. While, when I am there to support Kevin, well, I am his mum! Kevin tends to look at me for input, getting that indirect approval, if he's said the right thing.

It's what any young person does in an unfamiliar social context. We want Kevin to develop his own ideas and have more opportunity to speak up for himself. It's great that he has that learning opportunity and guidance through NACBO, but also through us his family.

Capacity-building also influenced family members and other people (teachers, employers, support workers, colleagues) to hold high expectations for people with disability, observe cues and listen to feedback, support people to have a say about decisions and directions in their life (set goals) based on individual preferences and interests. Across all stories of change (Appendix C), people gained greater say and confidence, which were core to NACBO capacity-building.

For some people with disability gaining greater leadership in life meant they were supported to leave or not enter congregated settings and groups (day programs,

boarding houses, disability employment) (for example Stories by Mandari; Liam (inclusive education), Monique, Bella, Peter, Gabriel, Mateo, Dora, Melissa; Appendix C). Support to live a typical life in the community meant that people had access to a wider range of opportunities and making choices about everyday life.

A few people with disability were also supported to build their capacity to speak up while living in disability (closed) accommodation. Marika became a self-advocate in the place where she lived. She said that learning to speak up for herself and others through the Consumer Support Group, was valuable for her self-esteem, learning from the leadership of her peers, and working towards making changes to improve how services were delivered.

3.3 Connections in the community

A central outcome from the NACBO capacity-building approach was people with disability and their families feeling more connected to their local communities and the people around them. In most of the stories and interviews, people and families emphasised the importance of connection, relationships and sense of belonging.

People with disability spoke of newly developed, intentional and meaningful relationships and strengthening connections over the years. Outcomes from capacity-building included identifying and developing social connections as part of work and community life; and intentionally investing in and forming new connections and relationships with people in the local neighbourhood (Appendix C).

In the NACBO survey many respondents said that people with disability took part in ordinary community activities or groups (43%); made new connections and friendships (42%); or participated in civic activities (voting, joined a committee) (13.5%) (Appendix D. Table 14). Feeling connected to people and places meant that people with disability felt they belonged to their local communities. Relationships in the local community resulted in social connections with colleagues (Leon), a bus driver, other students in class (Isabelle), local baristas (Christie), other dog owners living in the same street (Nina). The relationships meant people were known and connected in their communities and places of study, work and home. An approach was to develop these connections and activities 'one-person-at-a-time' drawing on personal interests and preferences. One such story is of Bella who lives in a regional area.

Moving out of an institution to live in her home

Eve, Bella's sister said: Bella, my sister and I are from a large family. Bella lived in the same institution for 47 years. In 2014, Bella moved to a home close to where I live with my family. I manage and coordinate a number of support workers to ensure Bella can live a good life in the community, has more choice about the support she receives, the daily activities she does, and to connect to her community.

The transition to an ordinary life took many years from the day I first connected with [the NACBO organisation]. The NACBO staff were instrumental to our planning. Bella requires 24/7 support to live in her own home.

It took close to seven years of planning, learning and investment in my skills, in visioning and working towards an alternative means that with the support from NACBO we have now achieved an ordinary life for my sister.

Bella's quality of life has improved significantly. Bella has choice over important things like where she lives, with whom she lives, who supports her, the types of activities and daily living she gets to be involved in – all that has changed. Bella enjoys gardening. She also sells small plants on a social platform, she regularly attends Karaoke with me and my friends, or with support. We make sure Bella has different opportunities to take part in social and community life.

3.4 Chosen home.

A long-term outcome of NACBO's approach to capacity-building was choice about where and with whom to live. Some people lived with their families due to younger age or prioritising other goals. Many people lived alone or shared with cousins, family friends, housemates without disability or were housesitting (for example, Bernie, Christie, James, Benjamin, Melissa, Leon, Appendix C). About a quarter of respondents (16%) to the NACBO survey said that the person with disability had moved into their own home as a result of capacity-building activities (Appendix D. Table 14).

Depending on their age, people with disability, with the support of families and allies, were exploring ways to live in the community, taking the time to find out what they wanted and taking the steps to make it happen. Other people had already achieved various ways to live in their own home. Some people were supported to leave congregate living and disability employment.

Tom – Moving into a home to call my own

Tom's story is told by his mother Ruby and a NACBO mentor.

Tom lived with his parents and siblings in their family home until 2005. At 23 years he had a short stay in a disability residential care facility, where his levels of anxiety were heightened to the extent that his family removed him for fear of his safety. Tom returned to the family home. His family were unsure what his future would look like. They were looking for other ideas.

A few years later Tom's mother Ramona was sparked by stories she heard from one of the NACBO organisations], about a woman with complex disabilities who had moved into her own home; Ramona thought to herself, "If she can do it then why can't Tom?"

Ramona spoke to the local coordinator of a small family governed collective (assisted by one of the NACBO organisations). They talked about her ideas for Tom living in his own home and agreed it would be a good idea. Together, Tom, his entire family and Circle of Support start to think about Tom moving into his own place. Tom was 34 years of age.

Moving into his own home, with a range of supports, including housemates without a disability, brought many new people, connections, experiences and social roles into Tom's life.

Today, Tom continues to live in his own home. Since 2014, he has taken up several paid jobs from delivering scripts for a pharmacy, to delivering pamphlets for a local real estate agent. Some of these paid work roles lasted for over 6 years.

Tom's Circle of Support supports him to pursue his passions for photography and painting. With their support he has set up a small card sales business based in local coffee shops he regularly frequents.

People emphasised their goals or achievements around living in their own home, having support and feeling safe in one's home and community. They wanted a place to call home, a place for individuality, personal tastes, a sense of place and community. They regarded having their own home as essential to their wellbeing. Often when people had their own home it was also a springboard to engaging in work and community life (stories by Leon, Melissa, Christie, Appendix C).

Melissa had attended a day service over two decades. She was now living in a home of her own and had joined the local gym and choir and was using her creativity to contribute to making banners with the Cheer Squad for a local Football club. Melissa now had connections and friendships in her community.

Many people said that building a social network was their goal. They were finding ways to connect to community and to other people through being involved in local community activities, like work, learning, training, creative endeavours (hobbies), sports and other interests.

Christie moved into her own unit a few years ago. Since then, her behaviour support restrictions had eased, and she established relationships with the owner of the local newsagent, and two of her neighbours, who looked out for each other. Christie and her mentor were exploring ways to connect to people. She planned to join a peer network of young women with intellectual disability and start a microbusiness to engage with the general public.

People found that moving out of home was often a complex achievement that could take many years to achieve. It required careful planning, resourcing, networks of support, and the availability of both personal support and housing, repeated capacity-building of the person with disability and their supporters (examples of stories, Christie, Bella, Monique, Arthur, Appendix C).

3.5 Economic and social contributions

Economic and social contributions include employment, volunteering, social involvement and leadership. People with disability gained a range of socio-economic and educational outcomes and found personalised, meaningful ways to contribute to their communities as a result of their connection to NACBO capacity-building. In the NACBO survey many participants reported being involved in one or more economic activities (paid and unpaid work, like volunteering). People with disability found paid work in the community (open employment 12.1%), started their own business (12.1%), and volunteered (18.1%) (Appendix D. Table 14).

Many people contributed in more than one way, illustrated in their stories (Appendix C). The stories demonstrate that when people engaged in work and social contributions, they gained confidence and skills through work and capacity-building. They also took on leadership, directly and indirectly influencing the places, practices and people they worked with, and the community more broadly.

Open employment

Some people participated in open employment, including Tom, Leon, Mateo, Ezra, Mateo, Leon, Conny, Laila, Dylan, James, Karelia, Nina (Appendix C). They said earning income was an important part of being an adult and being part of social and community life. The job gave them a sense of identity and meaning, learning and skills, new relationships, and meant they could contribute to living expenses. Some people were saving for extras (owning a pet, going on a holiday or to a concert) and making future plans.

People achieved paid open employment by using a variety of tools and strategies including customised employment. Achieving employment outcomes required focusing on a person's strengths and interests, developing individualised employment goals, and tailoring work roles. They also identified natural supports (family friends, business owners) and some people worked with a circle of support to help people and families work through the steps.

Support to move home and find paid work.

Tom used to live in a group home. His complex needs were not met, and he then returned to the family home. Over the years his family attended various events held by their local NACBO organisation. Tom was supported by his family and his circle of support to move out of his family home and move into his own place. Living in his own home, with the support of non-disabled housemates, has brought many new people, connections, places and social roles into Tom's life.

Tom has taken up several paid jobs from delivering scripts for a pharmacy, to delivering pamphlets for a local real estate agent. Some of this paid work lasted for over 6 years.

Tom, supported by his family and circle, keeps looking out for opportunities where he can be involved with the community and contribute through paid and unpaid roles. Currently Tom is learning how to become a Beekeeper in a local community class.

Many people found open employment through the steps of customising the job. Family and supporters gained understanding and skills in customised employment by attending information sessions through NACBO organisations. Families and supports engaged paid job mentors (support workers); or contracted a service to customise the work. Seeking out suitable and meaningful work roles that align with the persons' interests and potential contributions, providing nuanced support for the person and the workplace, are all part of the customisation process (Section 5). The stories by Conny, Nina, Dylan, Mateo and Leon (Appendix C) are examples which

speak of the employment outcomes and positive work experiences people gained as a result of families and supporters investing in customisation. Leon's story is an example of long-term customised jobs.

Customised employment

Tamara (Conny's mother): After engaging with the discovery process [through a NACBO organisation] to observe and learn about what we think Conny is intrinsically motivated by and interested in we decided on using customised employment. Learning the method and 'how to' of customised employment has been a huge learning curve for us as there is no workforce available to do this work. I feel our investment in implementing customised employment is working and making a difference.

Conny has started paid work in after school care which aligns with her interest in children, and she is getting to right level of input, stimulation and support from her job coach to grow and gradually become more independent in her work role. This opportunity came up because the job coach followed the steps of customised employment in identifying workplaces, interviewed them and looked if they were open to customising a role for Conny. That all occurred before Conny had even stepped a foot in the door.

As a mum and coordinator for Conny's paid mentors and job coaches, I could not have learnt this method on my own or put it into practice without the input and learning, and personalised conversation I've had with the NACBO organisation. They connected me to the peer group members and international guest speakers, all this made an enormous difference to learning this procedure, and Conny having the right level of guidance to find and grow at work.

Participation in paid work brought about benefits for people with disability – confidence, skills development, sense of belonging and purpose, material and financial benefits, connection to community and friendships. The workplace and people at work also benefited. In some stories, business owners, employers and families spoke of the added value and opportunities for social change and inclusion that had resulted from employing people with a diverse skill set and experience. Laila's and Ezra's stories of change are two examples of how people with disability added great value to the business and organisation they worked for, and how growth in people's confidence and leadership could bring about (small and larger) social change and more inclusive systems and workplace practices to their places of work.

Micro-businesses

Micro-businesses are another means for people to make meaningful economic and social contributions. Designing, creating and running a micro-business was an opportunity to learn new skills and gain in confidence, become connected to their local communities, earn income and take pride in a contribution. Jerry's story is one of many examples of building the capacity of people, their families and supporters, to create and run his own business doing something he enjoyed and generating income.

Building a micro-business

Nate, Jerry's long-time paid support worker and ally explained: Jerry is a vibrant 21-year-old man who has worked with [NACBO organisation] to develop and build his own lawnmowing and gardening business. Jerry used capacity-building support over three years during the stages of the business development.

Jerry is a loud guy with a great sense of humour, loves commentating the football, and loves a ride-on lawnmower. After leaving school, his family and support worker identified ride-on lawnmowing as a job option. Supports were initially managed by another organisation; however, they couldn't provide a consistent vehicle on time which upset Jerry's routines.

In 2020, [NACBO organisation] joined Jerry's family and allies to advocate for increased NDIS funding and qualify for School Leaver Employment Support (SLES) funding. [NACBO organisation] worked out creative solutions, strategies and capacity-building. They supported Jerry and his team to build their skills to develop a business plan, understand and navigate NDIS funding, and apply for small grants for gardening equipment. This was a big learning experience for everyone involved.

Since starting his business, Jerry has saved and bought a trailer and a ride-on lawnmower. The next steps for Jerry's business are to explore employing additional staff to grow his business and do more marketing and radio advertising.

Jerry's business recently won a state award for excellence supporting employment outcomes' category.

In many stories, people with disability had a micro-business amongst their other economic contributions in paid employment or volunteering. The micro-businesses were aligned to the persons' interests and goals. Examples were Candy running an art business; Bella sold pot plants; Melissa made cards and canvasses; Gabriel sold

his paintings and art works with other two young people; and Mandari, who was still in high school, explored a business hand-rolling and locally selling sweet treats.

Social and economic contributions

People with disability participated and contributed socially and economically in their communities in other ways, for example, through volunteering, doing things with and for their neighbours and community, and through demonstrating leadership.

Work experience leading to study for a career in film.

Melissa, Benjamin's mother said: Benjamin is a creative young man in his early 20s. He enjoys writing stories, making film and video, and drama. Benjamin loves being social and learning from peers his age. He lives with autism and is aspiring to a career in film or screen writing.

During his high school education Ben wanted to undertake an internship at a local radio station. Because he loved the experience, we continued and set up an ongoing role for Benjamin at the radio station. We designed an individualised work placement.

Knowing that Ben finds it most challenging to orient himself in a new social environment, when we created the ongoing role, we asked the supervisor he already knew from his internship to be a paid mentor for a few hours. We used NDIS funds to pay half a day of Ramona's time to have personalised support to learn the tricks of the radio trade. Benjamin was eager to learn and felt confident as he was with people he knew and trusted. This was the first most powerful thing we did the funding, working with industry-insiders to build Benjamin's skills and confidence around something he loved doing.

In a short time, Benjamin learnt everything he needed to run and host a radio show. He remained involved with this radio station for over 4 years (2016-2020), until he moved interstate to attend university and study screen writing.

All this was possible because of the [NACBO organisation] inspiration and stories, tools and resources, ongoing encouragement and guidance, including how to self-manage and recruit mentors, and build on 'naturally available' supports, like the radio manager. They helped us to intentionally customise and create an environment of success for Ben.

3.6 Planning and safeguarding for the future

An important outcome for people and families involved in NACBO capacity-building was having clearer ideas or making concrete plans and safeguarding 'a good life' for the future. People with disability and families planned for the time post school, when many structures and social connections change for all young people. Planning for work and employment began for many while young people were still at school or had just left.

The NACBO model of capacity-building uses a life course approach. Some people and families connected to NACBO organisations started to plan early for a future where existing support structures and people they relied on were no longer available. Family members, people with disability and staff reinforced that for community activities, work, education and living in one's home to be meaningful and sustainable in the long term, people needed to feel socially connected. Creating a network of people who genuinely care to uphold a person's interests and preferences was considered a first major step to safeguarding a good life.

For some families the planning, gathering of ideas, resources, assessment of options, finding support and building one's capacity to navigate important life stages, commenced years in advance. Mandari's and Conny's families started planning and exploring options for future employment and home while Mandari and Conny were still in high school. Other families, like Damian and his parents, put considerable time into imagining and securing a good life in their community, if they were to pass away.

Structures to safeguard a good life for the future

Damian's mother, Pam said: My husband and I come from a small family ... meaning we don't have much extended family. Starting our journey with the [NACBO organisation] changed things for us. First, we used the social role valorisation approach to create more opportunities for Damian to socialise and meet people ... Later I wanted a 'brains trust' to help us to support the ideas and life we were setting up for Damian and his future.

The NACBO organisation workshops on Microboards and on circles of support were very important for us. I met people at the workshop who are very experienced in Microboards. The facilitator later went on to mentor our family, on how to achieve these things in practice, there is a whole lot of technical detail involved, legal considerations. Now, a few years later, we have a registered Microboard. It is a small, incorporated body, it will be directly employing Damian's paid mentors.

The Microboard can also apply for grants, own property ... and we have a constitution. It is set up in a way that it is harder to be wound up. If my husband or I are hit by a bus tomorrow, there are 6 people who know Damian very well, who are not his family, who do not have financial interest or other conflict of interest, only care for Damian and his wellbeing and achieving his vision of a full life. The board members can change over time.

Damian is now in his 20s, with the Microboard and Damian's circle of support we are working on putting his vision of finding employment into reality. So far, Damian hasn't been able to secure work in an ongoing way. He needs predictability and regularity to a level that we have not found an employer willing to create that environment. We started exploring a micro-business where Damian will digitalise photos and documents ... having the business structure will make it easier to adapt in the future, when he wants to do something different.

Succession planning was a complex outcome to achieve. It meant working out the practical and legal arrangements for how people with disability could continue an included, self-directed life in the community once plan nominees were no longer available to provide guidance and safeguard a persons' life goals. People and families with strong succession planning were generally people who had achieved their other immediate life outcomes, like in Monique or Gabriel's story (Appendix C).

3.7 Challenges to achieving outcomes

Most outcomes took time and many steps before they were achieved. Often, the goals required longer term planning and repeated engagement in capacity-building for people with disability and families to create change.

Living in a home of one's own, depended on the availability of affordable homes and family resources to secure one, or sufficient funded supports for the person to live in their own home (Peter's story below). Employment outcomes further relied on employers adopting inclusive and customised employment practices and holding high expectations for people with disability. Sustaining employment was also affected by workplace changes: businesses closing, allies (managers or staff) leaving, restrictions like Covid, exclusionary or discriminatory work practices, and lack of ongoing employment support for the person to succeed (examples by Dylan, James, Mateo). Sometimes carefully developed plans turned out to not work and had to be revisited.

Challenges moving into own home

Peter said: Hi, I am Peter, I am 46 years old and have not had a chance to do what I want. I don't have any family members in my life. I have lived in a group home for close to 30 years. When I was still a teenager, my foster parent got very ill, and there was no other place for me to live.

Where I live, the workers are nice, I live with five other people with disabilities I didn't choose. Sometimes I get angry at my housemates, when they are too noisy or loud, it's not their fault, it is not where I want to be and live.

Since the NDIA planner asked me seven years ago, if I would like to move, I have kept telling my good friend Sabine, I know from work and my other friends, I want to move and get a place of my own! Some days, I would ask them four times a day if they had any news for me. Recently my friend Sabine found [NACBO organisation] to help us plan how I can move out of the group home.

I know it would be impossible for me to move out if I didn't have my friends. People say that the NDIS system is complicated. Sabine and [NACBO organisation] think we should start a group called a circle of support to help me plan this move and reaching my goals. The NDIS funds a facilitator to lead a discussion with me and my friends.

About a year ago, my friend Sabine helped me rent a little two-bedroom house in my local area. This change has been really good! I am brushing up on my skills that I just didn't use or couldn't learn at the group home. On Tuesdays, after work, I go to my home. There I plan my meal and cook it with support. Afterwards I build Lego or listen to music. My friend, Sabine, says we need to make sure I'm safe in my home to begin with, and then the NDIS can save money.

Unfortunately, I have to go to a special court to fight for my NDIS funding, so that I get the support to spend more than one day at my own place. The NDIS wants me to live in a house with two other people with disability. I don't understand why. I prefer to keep my house, the unit I am renting, and slowly want to spend more time there.

Postscript: Given the time for anything to happen, and Peter's very strong desire to move out of the group home as soon as possible, Sabine and the NACBO staff member workshopped how Peter might be able to live safely and well in his own home with a relatively small amount of support he already had access to. Peter now thrives on the new freedoms he has living in his own place!

Connecting with other people took time. Making new friendships, people who share one’s interests, and become a reliable friend over time (beyond a connection in the community) could take careful planning of social roles, routines and opportunities to connect with others. The tension between goals and time was frustrating for young people who recently completed school; people who left a workplace or worked in a more insular role; or people simply did not feel they had many people in their life wanted to extend their social networks and relationships (stories by Azra, Christie, Damian, Kevin and Nina).

Tensions about preferences between people and their family made it harder for some people to achieve their goals. For example, at first, some of Bella’s family did not agree Bella could leave an institutional disability accommodation and live in her own home in the community with support. Bella’s sister Eve had to convince and “negotiate with the nay-sayers” within her large family. Eve said her siblings were happy with the status quo and were risk averse, not wanting to take on extra responsibilities.

Outcomes were harder to achieve when people and families had little previous access to capacity-building over their lifetime. Family’s ideas about what a ‘good life’ for a person with disability looked like could include low expectations, perceptions that people had few rights or little capacity to take risks and make decisions for themselves.

Raising expectations of family members

Ramona’s grandfather Bogdan was her sole family member and plan nominee. Bogdan said he wanted to look after his granddaughter as long as he could. Bogdan’s ideas of a good life were based on “being looked after and having access to functional support”. Ramona and Bogdan said that after he was involved with a 3 month NACBO organisation workshop series and peer group, he started considering Ramona’s emotional and social needs, supporting the idea that Ramona had a right to make her own decisions, like getting a driver’s licence.

3.8 Outcomes for family members and supporters

NACBO capacity-building also benefited family members – parents, siblings, grandparents and extended family – and allies or friends supporting a person with disability. The benefits were experienced at individual and family levels.

In the NACBO survey two thirds of respondents were family members. Three-quarters (73.1%) of respondents said they had shared new information with others; felt more empowered (64.2%); or changed what they were doing and tried something new (54.4%) as a result of their involvement in capacity-building. These findings underline how holding higher expectations and connections to peers and like-minded people intersected and resulted in personal growth and leadership in every-day life for family members and supporters involved in NACBO (Appendix D. Table 15).

As evidenced throughout this Outcome section, family members accessed capacity-building over the life course. Family's expectations gradually shifted when they were exposed to different ideas, stereotypes and challenges to low expectations around disability (Section 4.4). As their view changed, they took actions to support a more self-directed life for the person with disability. They engaged in an ongoing reflective process, learning to gradually encourage the person to have more say in their life (story by Kevin and Mona, Appendix C).

Connection to peers and other family members, who shared similar experiences, values and ideas about inclusion, were another outcome from NACBO capacity-building (Section 4.1). Family members said they felt less alone, having found like-minded peers. Some families experienced connection to NACBO organisations as similar to belonging to a social movement.

Family members spoke of a wide range of personal growth and leadership they took on in every-day life. Taking on leadership made them feel knowledgeable and empowered to lead their own change. Family members were involved in many aspects supporting a persons' preferences and goals: coordinating, instructing, hiring, supervising paid supports, or mentors and industry-insiders; learning about, envisioning and planning together with the family member how to create an authentic life aligned to their preferences (stories by Benjamin, Darren, Monique). They became more 'comfortable' to involve and ask for support from naturally available allies and relationships (e.g., to form a circle of support). They regarded changes as outcomes of personal growth, underpinning family leadership in everyday life (see stories by Benjamin and Melissa, Mandari and Reena, and Clementine).

Section 4.2 discusses the range of leadership opportunities and roles for family members from the NACBO capacity-building approach. Investing and gradually building greater family leadership was part of the model. Across the NACBO organisations, family members supporting someone with disability in their life, were involved in developing content and sharing stories with other people (story by Monique); as volunteers and paid facilitators, running and presenting at peer groups

and other peer-based activities (story by Darren and Kenia); employed staff in NACBO projects and programs; and representatives on boards, advisory panels, and other NACBO governance.

The outcomes where families felt valued and listened to; grew in confidence and capacity to lead, manage, present, advocate, and challenge negative and biased views (Clementine's story of personal growth and becoming an advocate). Family members took their skills and confidence into their work life and other relationships (Mandari's mother's story of becoming a peer educator and advocate for inclusive education).

4 Impact on the lives of people with disability.

What impact does the NACBO model of capacity-building have on the lives of people with disability?

The NACBO model of capacity-building led to connection to other people who hold high expectations to ideas about authentic inclusion, and to organisations that provide the knowledge and skills building about achieving the expectations. Other impacts were leadership development opportunities and roles for people with disability and family members. These impacts contributed to people's capacity to achieve the outcomes described in Section 3.

4.1 Connection to people, peers and capacity-building organisations

Being connected to NACBO afforded people, family members and allies supporting a person access to a wide range of capacity-building activities (Appendix A) and tailored information on diverse topics. The topics were across the lifespan from attending the local school, carving out work, creating a home, supported decision making and planning for succession. Information and developing capacity were designed to raise expectations and inspire ideas for people with disability to live an authentic and full life.

Over two years (2020-2021) NACBO delivered 227 workshops to 2,684 participants (people with disability, family members and professionals) and 141 webinars to over 5,500 participants across Australia and some international attendees. Over 150,000 users accessed NACBO websites and online resources (podcasts, planning tools, videos, written resources) (Appendix A.).

Staff and leaders in the interviews emphasised that the NACBO approach to building capacity achieved the most impact for the person when people with disability and families engaged in followed up conversations, were **connected to and learnt from peers**, and had opportunities to share their experiences (e.g., present at conferences and workshops) and build other leadership capacity (Section 5.1).

As a result of being involved with NACBO activities, most survey respondents said they were more confident (84%), learned and tried something new (81%), and were more connected to other people (75%). (Appendix D. NACBO survey, Table 13). The stories of change (Appendix C) underline findings about the importance of

connection to other people and **combining different levels and types of capacity-building** to achieve broader outcomes for people with disability.

The stories highlight the benefit when people combined multiple capacity-building activities to achieve holistic and all of life outcomes. For example, Mateo received facilitated capacity-building follow up to inspire and plan his move to his own home which he shared with his older brother. Leon worked part-time for over 10 years at a local small business in a regional town and rented his own unit, he also volunteered at a local farmer's market. He achieved the things he wanted for his life, also connections and new friends through building his capacity. It enabled him to employ a support worker who helped him find work he liked. The idea to pay someone to find a job came when his parents attended a NACBO session about how to make a good life. Previously, Leon was bored and underpaid at a disability employment service.

“We had a meeting at Mum and Dad’s, and I told [name NACBO staff] what I wanted to do. Then we put it in motion. I got a house and I moved to [town] and that’s how we got the ball rolling... I love being in [my town] because there’s heaps to do. I can go to the movies or my support worker we go to the movies together, to the cricket, too!”

Through lots of discussions with the worker, Leon decided he wanted a job around and with other people. When they found the job that met this criterion, with a small local business, Leon completed a 3-month trial, and they made worksheets so all the tasks were clear. He has now been employed for over 15 years.

“When I first started, it was the 3-month trial and in that 3-months was my support worker. [Lydia], she helped me! She did a manual for me with all the instructions that I follow so I can do all my tasks.”

Mandari’s family learned about inclusion in education which helped them to navigate and successfully advocate for Mandari’s inclusion at a mainstream school. Tej’s family, like many others connected to NACBO capacity-building, learned about self-managing funding and supports (hiring, employing, supervising, coordinating paid workers). Many families who achieved important steps and outcomes for the person with disability, also took up leadership roles, through people and family members sharing their experiences with others at conferences, workshops or webinars. A parent explained their process to gain confidence and skills to self-manage funding and support:

When the NDIS came, families had a lot of questions ... I attended one of the NACBO workshops ... Afterwards I thought, I could never do that [self-

manage] my daughters funding ... they kept sending me emails. I attended more webinars and other things. Later, I joined a peer group on self-management ... From the other parents in the group, I learnt many tools, ideas and gained confidence to try it out myself. I started experimenting. (Tej's mother Lamia)

Through repeated participation in different types of learning (workshops, webinars, conferences, resources) and engaging in follow up with other people (NACBO staff and peers), people and family members increased their expectations about what was achievable, imagined a good life, and gradually grew their confidence and capacity. This growth over time impacted their lives. Supported by family, friends and allies, people with disability who were connected to NACBO organisations stepped towards greater self-direction and authentic social and community inclusion (3.3 Outcomes).

4.2 Impact from leadership development and opportunities

The NACBO model includes investment in the leadership capacity of people with disability and families. Opportunities included development of presentation skills, sharing stories, coordination and facilitation of peer and advisory groups, taking part in co-design and policy making, content development and governance of NACBO projects. These approaches had an impact on people's confidence, skills and leadership opportunities. Details of the stories are in Appendix C.

Including the lived experience of people with disability shaped the planning, design, scope of delivery and the content of some capacity-building activities (Story of Co-design council, Appendix C). Paid employment as part of NACBO organisations and projects created meaningful opportunities for people with disability. People developed career skills, while influencing the design, delivery and content of capacity-building to peers (see for example, Ezra and Bettina).

Some people with disability were employed to deliver and facilitate workshops and capacity-building (Sammy, Karelia, Bettina), or paid as consultants (on boards) and peer mentors (Kevin and Leon), others joined a peer group. Twenty per cent of respondents in the NACBO survey said that the person with disability had joined a peer group.

Many people contributed to leadership by sharing their stories and educating others through NACBO resources (podcasts, video, social media), for example Dylan and Benjamin; by being a speaker or presenting one's story at events and activities

(conferences, workshops, TED talks) for example, Randy, Simon, Jerry; and involved in self-advocacy or leading peer groups (Conny, Sammy, Marika, Randy, Ezra).

A positive by-product of this leadership development was work also undertaken in the person's local communities. Many examples of people and their families seeking out opportunities that educated their local communities around the benefits of authentic inclusion. This occurs through joining local groups, attending relevant functions and meeting with change makers that could genuinely advance the participation of people with disability locally (Appendix C).

This inclusive approach afforded visibility and leadership of people with disability to the wider public, their peers, communities and in policy (examples of stories, Karelia, Randy, Ezra, Leon). Some leadership roles were unpaid, where the people involved said the opportunities built their capacity and they made an impact. They said they learned presenting and recording their stories, and advocating for their rights (Randy, Sammy, Marika).

Leadership influencing change

Ezra said: It's been 5 years since I started this work here, I am an office admin assistant. I also organise the disability advisory council for this organisation. My role with the disability advisory council is to support the members. I also help with the preparation of easy read material, send invitations, set up the meeting, support people with disability to feel comfortable during the meeting.

Last year, I was invited to present at a workshop on supported decision making (for supporters and parents). I was a key guest speaker. I spoke about how I want to be supported in making my decisions. I wrote up a manifesto called, "How I want to be supported". Preparing and presenting for the workshop really helped me to be clear ... that people can put me in the driver seat, it is my life. And I want to make the choices that I want to make. I felt more confident after it.

After the workshop, I told [my manager] it would be a good idea to hold a similar workshop for the advisory council. The council agreed to the idea. Then we invited a guest speaker to come and talk to the members about supported decision making.

To have work is very important for me. It allows me to live in my own home and to rent my own place, next week I have a housemate moving in. I am saving up to go to a *Pink* concert later this year!

The manager said: A reason we started the disability advisory council was that the [NACBO organisation] board felt we were not hearing from people with intellectual disability what sort of capacity-building they wanted and how we could support their voice. We realised we needed to create learning space in which material could be easily understood and we could receive feedback and ideas from people with intellectual disability. It wasn't enough to have a person with an intellectual disability sit at our board meetings, or to hear only from family members. The advisory committee is now more than a representative model and is able to provide much stronger influence internally and externally.

Employing Ezra and building her leadership to present and speak at the workshop has had a number of flow-on effects for our organisation. These new developments would not have happened without Ezra's leadership and employing a person with lived experience. It has enriched and diversified what we do as a NACBO organisation!

NACBO also invested in family leadership development and opportunities. Family members were involved at all levels of the NACBO governance decision making, advisory groups and board, employed as paid staff and facilitators in capacity-building activities, invited as paid contractors to present at peer led groups and conferences to bring real-life experiences to all capacity and content development (Reena and Mandari, and Monique).

The NACBO approach was investment in leadership over time, providing opportunities to grow and influence change at family and community levels. The impact of this approach created a sense of empowerment for people and families (Reena and Mandari, Monique and Tammy). Families also contributed to driving social change at community and policy levels (Clementine). One of the benefits of investing in the leadership of people with disability and families was that it helped to create change. Other people could see what was possible and they had added trust and authenticity when peers shared and heard each other's stories. This also created an intergenerational approach to leadership development.

4.3 Changes in the lives of people with disability.

What changes are people experiencing and are people achieving their good life from participating in the capacity-building?

People with disability experienced a broad range of changes at a personal and family level. Evidence from the NACBO survey (Appendix D. Table 14) and stories of change (Appendix C) showed that people with disability grew in confidence to speak up, demonstrated greater self-direction, had more leadership and choice in their life, set goals for the future, connected to other people and peers, participated in typical social, economic and community life (education, work, civic roles, community events, sports), moved and lived in their own home and self-directed supports and funding packages (Outcomes 3.3).

People with disability achieved a good life by building their capacity and confidence to express their needs and wishes, to speak up (Laila, Isabelle, Ezra, Leon). Their supporters became more confident to lead change together with the person they supported (stories by Kevin and Mona, Arthur, Benjamin). Simon's story demonstrates the broad impact building capacity had on people achieving a good life and positive impacts on the family.

Through changing expectations about disability (how families perceive, think and speak about disability), families acquired capacity and felt empowered through NACBO learning, skills development, follow up, and connection/learning from peers to drive change in the person's life. Simon was supported by his family to maintain and grow his social connections in his life. He uses tailored communication methods to stay in touch and to speak up for himself (to introduce himself and his interests to others) which Simon and his mother develop together. The importance of building relationships is further maintained as Simon develops and grows his business and participates in other community activities.

Important capacity and skills were used by many families and supporters (Appendix C Stories of change) to assist their family member achieve a good and typical life and affect change. The changes included: holding up a vision and seeking out suitable and typical opportunities for the person; being comfortable to ask for help and involve other people in one's life (identify natural supporters, also paid professionals); learning to observe and understand a person's intrinsic interests, motivations and behavioural cues to make suitable work and social roles for the person; self-manage funding and coordinate paid supports and lead change in the person's life (Section 5).

4.4 Impact on shifting mindsets

What is the impact of how the NACBO model shifts mindsets?

The NACBO capacity-building approach shifted mindsets and raised expectations for people with disability on individual, family and community levels. Shifting mindsets, embracing what typical inclusion and a good life can be and holding high expectations for people with disability, was more likely when people and their families were receptive and open to new ideas, or actively searching for alternative models of building a good, included life. These shifts in expectations from participating in capacity-building contributed to achieving the outcomes described in Section 3.

People with disability, family members and staff reported NACBO changed expectations about the lives of people with disability. Capacity-building activities emphasised people's right to participate as valued members in their communities, have typical opportunities and valued roles, and receive support to achieve a good life, similar to other people, and with the heightened benefits that come with this. Even small changes in the perceptions of people and families about expectations and language for disability were regarded as successful short-term impacts of capacity-building.

The part of the workshop that stayed with me were people's stories of living a better, fuller life. I was thinking ... that's what I want for my son! I changed my perspective quite dramatically. At the time, it wasn't how my son was living, he was attending a day program and had little choice. We didn't even consider other options for Kevin's life! (Mona, Kevin's mother)

Other impacts on mindsets from capacity-building were increased awareness of the diverse options to seek out ways for people with disability to participate and contribute to their local communities, to build and maintain relationships. Family members gained higher expectations and greater confidence to get to know the interests (intrinsic motivations) of the person with disability and how to turn these into meaningful roles and participation in social, economic and civic life. Changes in expectations occurred when limiting beliefs of people with disability, their abilities and rights were positively shifted.

Inside I always knew our daughter Mandari belonged to a typical school. We had many professionals involved in the early years, we went along with their recommendations ... During the first workshop, I realised that Mandari has the

right to attend mainstream school! ... It was a total shift of mindset. I remember texting my husband saying, "Mandari will attend mainstream school". I was passionate about high expectations, dreaming big and supporting her to achieve that. This day changed us as a family! (Family member).

Connection and belonging to 'like-minded' families was important for shifting mindsets. Family members and people with disability could see from their peers that their hopes and high expectations were not exceptions but reflected in real-life changes realised by people and families. One person with disability employed by a NACBO organisation explained, "Seeing is believing, you have to see it, to believe it".

People and families sharing their stories and people with disability in leadership roles contributed to shifting assumptions about disability. Some family members and people with disability described their connection to NACBO like feeling part of a 'movement' or having found like-minded people.

Some people with disability and their families pursued inclusion in a particular life domain, remaining involved in disability specific settings in others. For example, Gabriel, a talented painter and sculptor, with the support from his family moved into his own home. He developed his skills to speak up and live in his own home, while his mother managed and coordinated his paid support workers (Gabriel).

5 Effectiveness of NACBO processes

The NACBO model has three main processes to build skills, capacity and confidence and to change mindsets. These processes are driven by a range of principles about social inclusion and belonging (Section 2). The processes are learning and information, follow up, and leadership development. These three processes interlink to build the capacity of people with disability and the people who support them over time. The processes adapt to the person's situation and preferences as they change. This section describes the processes of the NACBO model and how they build capacity and change outcomes for people with disability. The section ends with a discussion of the challenges and opportunities for the model and the NACBO Alliance. Implications from these findings are in Section 6.

5.1 NACBO model process

How does the combination of processes in the NACBO model interlink to change outcomes?

NACBO model principles and processes were interlinked to build capacity over the life course. These steps resulted in outcomes for people with disability. The NACBO organisations shared a commitment to high expectations for people with disability. This commitment had flow-on effects for the other parts of the model to change outcomes and create leadership opportunities. The processes of learning, follow up, and leadership development were interconnected across time, responsive to people's preferences and changing situations.

Experience of engagement with NACBO

In the NACBO survey (Appendix D), participants were asked to rate the NACBO organisation they had most contact with. Most said 'excellent' (65.6%) or 'very good' (14.7). Only 1.5% rated NACBO organisations as 'poor'. Most people (88%) also said they would recommend a NACBO organisation to someone else (Tables 16 and 17).

The participants also noted a single word or image that best described their experience with a NACBO organisation. The most common words were positive support, empowerment, inspiring, helpful, inclusive resource, and supportive (Figure 5.1; and Appendix D.).

Figure 5.1 Word that best describes your experience with a NACBO organisation



Building high expectations

NACBO organisations shared a commitment to people with disability being represented at all levels of their community and living an ordinary life with opportunities similar to other people. This consistent view of authentic social inclusion achieved diverse outcomes for people with disability, aligned with the Australian Disability Strategy 2023 objectives, as evidenced across all stories of change (Appendix C).

Being really clear on the purview and scope of the work of social inclusion and how we do that collectively ... That absolutely brings strength ... and then drives those outcomes home in relation to people with disability being included in their communities. (NACBO leaders)

High expectations had an on-flow effect to the other parts of the model which worked to change outcomes and create leadership opportunities. High expectations affected how people and families engaged in capacity-building. The model sought to facilitate an openness in the person and family to repeatedly invest in developing capacity, to create or search for possibilities and tailored experiences that met a persons’ interests, and to advance personal growth to live an included and good life. An example is how Mateo’s family invested in capacity-building strategies to help Mateo envision his move out of his family home.

High expectations and situated capacity-building

Mateo's mother, Jenny: Our family has been involved with [NACBO organisation] for close to 14 years. Over the years, I attended many, 10 or more, workshops on different topics, two conferences, and had follow up conversations with the NACBO organisation. I was also part of a peer network for parents and supporters.

For us it was clear, we wanted Mateo to move out of home one day, like any young person. It is an important milestone to become more independent, make daily decisions, and live one's own life. Since his mid-20s I kept checking in with Mateo, if he wanted or was thinking about moving out. He kept on saying, "No, I want to stay here [in the family home]". I spoke to Mateo's mentor, they suggested we run a visioning session around Home for the family. We worked through a lot of the details ... I realised Mateo could imagine his future better, he had a real vision afterwards, he started telling everyone he would move out in six months!

We ended up buying a small flat close by, we were lucky enough we were able to do it, having a long tenancy was really important for me. Over the next months we worked out all the details, how would his support work, getting to work, medication, socialising and so on. It ended up being easier than we thought. Because Mateo's home is in our neighbourhood, a place he already knew well. Within a week he knew the main walking routes by heart.

The long term plan is to have an ILO [Individualised living options] application with the NDIS. [NACBO organisation] are guiding us with that because the process is very new. In the meantime, it worked out that Mateo's older brother wanted to move, and the two brothers decided to move in temporarily together. It was a really easy transition while we are in the application process for housemate support.

Moving out of home at 28 years was a big step for Mateo. He grew immensely in his skills. He had to learn how to use the new appliances, like the washing machine, how to get around his neighbourhood, and many other aspects of everyday life.

Mateo loves where he lives now. He hardly ever comes home, even though it is a five minute walk! I started a weekly family dinner to have all the kids together, because everyone was happily doing their own thing and making everyday decisions by themselves.

Incremental processes

The three NACBO processes (learning, follow up, leadership) were interconnected and layered across time to respond to people's preferences and situations. For example, goals around social connection and friendship of a young person with disability would change when they left school. As young people move into adulthood, they may want to find a partner.

NACBO layer the content of the workshops and events to sort of illuminate certain aspects in people's thinking that might have occurred over the years, why this person is currently in this particular situation, and what their life could look like ... the questions that families have will usually come up in follow up workshops and discussions. (NACBO leaders)

Layering the topics formed a holistic approach to building capacity. For example, to support employment opportunities and tailored work roles, people and families were offered a range of resources, follow up opportunities (e.g., circle of support, discovery meetings) and learning opportunities. These resources facilitated imagining, questioning, learning through observation and reflection about a person's motivations and input from others. For example, peer networks were useful to explore topics about customising employment or creating a microbusiness.

Many family members reported attending specific workshops and network groups repeatedly, or at particular times, when these topics became relevant to the person's life and goals (for example, story by Conny and Tamara, Appendix C). Attending follow up activities, such as tailored peer groups, helped people to break down tasks into achievable actionable steps. Follow up conversations and mentoring from NACBO organisations or other people assisted them to resolve complex challenges. An example was how to apply for funding to support customisation approaches.

The NACBO approach supports people and families to take a more considered approach. For example, through working in workshop formats that run over a few weeks or months and involve different perspectives ... from presenters, importantly peers and other families ... What was particularly good about that conversation, there were other family members in the room, who were ... at other places along that road and they could share that perspective. It's been remarkable ... I've seen families turn 180 degrees in the course of half a workshop because of the narrative they hear from other people ... We create that space where people can start to mine the underlying interests behind the position they take. (NACBO leaders)

5.2 Process to shift mindsets

What processes are effective in shifting mindsets?

The NACBO principles and processes – learning, follow up, leadership – built on each other to gradually create capacity for new possibilities, identities and social roles for the person with disability. All three processes reinforced each other to shift expectations about what it meant for people with disability to live a good life and have leadership. Shifting mindsets was enabled through creating visibility and vision; new possibilities; long term investment in a person’s and family’s skills and confidence; and breaking down goals into achievable steps.

Alternative options

Many people who accessed NACBO capacity-building were seeking alternatives or had already changed their expectations about options to support people with disability. Exposure to peers with higher expectations led people with disability and families to become open to new ideas and build momentum towards change. High expectations (Section 5.1) were achieved through sharing lived experience stories that were diverse, authentic and relevant. As one family member said, “Seeing is believing”.

My son was born and all the staff at the hospital spoke about his deficits, nothing positive. I heard about this workshop in a nearby town, when I was there, I felt “Oh, my god, I have finally found my tribe!” (Anita, family member)

Darren attended a special education school. He was 20 years old when we went to our first NACBO workshop together. After hearing the testimonies from other families, knowing that there were alternatives, we had hope and a new perspective for Darren’s future. (Darren’s mother Kenia)

The mindsets of people and families shifted over time through repeated engagement in a variety of formats to learn and build capacity. They participated with peers to break down goals and challenges into achievable steps. They received personalised guidance and encouragement from peers and staff in NACBO organisations (Section 5.3).

We’re shifting mindsets by providing families with the confidence in their own views and aspirations ... a family will come to our workshops and be like “Oh, I’ve been thinking this for years; I didn’t even realise it was an option!” (NACBO organisation staff).

A mindset shift to envision high expectations and act on them required incremental and nuanced capacity-building for most families. The steps could mean working with

different members of one family, for example, to gradually work through assumptions or to resolve external barriers (access to funding, suitable supports, opportunities). Often shifting mindsets took a long time and involved building new perspectives, skills and identity with the person with disability. Families learned to navigate complex systems or developed specific capacity, such as hiring, recruiting and managing paid supports.

Expanded opportunities

Jerry's opportunities have expanded significantly since the NACBO organisation joined his team. As Jerry has become an adult, his family have struggled with his complex behaviours and difficulties with self-regulation. Over the past three years, the NACBO organisation have empowered his Mum and support team to advocate and secure the supports needed, think creatively about work opportunities, and strategically work towards living in his own home. All at a pace that is good for Jerry and his Mum. Jerry's mother said, The NACBO organisation "gets it ... It's been a massive learning experience."

In addition to support to navigate and grow his award-winning gardening microenterprise, Jerry has secured support to explore self-direction away from the family home. His most recent trip to accept his business award has involved intensive documentation to support why he will need 1:1 funding to live in his own home, and have the best opportunity for success. Going on this journey together has taken time, however it has provided a new vision for the future for Jerry and his family.

Three steps contributed to the effectiveness of shifting expectations for people with disability in the stories of change (Appendix C):

Visibility and vision

Expectations changed when people and families could see people with disability taking the lead in their daily lives, acquiring and holding valued roles and making decisions about their preferences. They also saw them in leadership positions in organisations, such as people with disability and families facilitating workshops, sharing their story, presenting their experiences and how they changed outcomes with the person with disability and their family.

Creating tailored possibilities

The NACBO approach to shifting mindsets was to focus on building the capacity of one person at one time. The person and family were offered mentorship and coaching to tailor experiences and opportunities to a person's interests, intrinsic motivations and changing situation in their life stage and preferences. They

accessed information and tailored guidance to navigate systems and work through their particular challenges. The stories of change all reflected this approach used by the NACBO organisations. Examples of stories using customisation to achieve employment outcomes included Nina and Benjamin's stories.

Long term investment

The third step in incremental capacity-building was long term investment in developing capacity and confidence of people and their support networks over their life course. Examples of longitudinal investment and how they contributed to changing mindsets over time were circles of support (Section 5.3).

As well as working with each person with disability and their family, the NACBO organisations invested in their leadership to influence policy and shift mindsets at community and governance levels. Examples of people with disability and families informing policy and programs included user-led conferences and forums, advocacy, and having a say on policy such as the Disability Royal Commission. Examples of shifting community attitudes and policy included Wandga and Karelia's story of changing attitudes in isolated communities, and Marika's story of influencing change within a disability group home.

5.3 Process to build skills, knowledge and capacity.

What processes are effective to build skills, knowledge and capacity of people with disability and their families and supporters?

The principles and three processes in the NACBO model (learning, follow up, leadership) were effective in developing the capacity of people and their families. NACBO organisations engaged participants through demonstrating examples of social change (raised expectations) for people with disability and families in learning activities. The engagement continued with follow up with individual people and families directly to try ways to achieve new ambitions in their lives.

Building confidence, knowledge and support networks

The NACBO survey found most participants felt more confident and empowered from their connection to a NACBO organisation. Most people (three-quarters) shared new information with other people. Over half the participants reported making changes in life and trying something new (Appendix D. Tables 13 and 15).

Across the capacity-building support and activities, engagement with information and learning were the most popular. People and families valued engaging in learning simultaneously creating connections with peers.

We asked [participants] what they liked [about the workshop series], one man with disability stood up and said, “It’s good to eat lunch next to somebody”. We really appreciate that ... our events are designed and intended for people to connect with others. It is powerful when you live with disability or have a family member with disability you may not get many opportunities to attend community events. (NACBO staff).

Participants also valued the combination of NACBO capacity-building offerings that included follow up and leadership development. For example, over half of survey respondents said they had participated in one-to-one follow up conversations or mentoring with a NACBO organisation, and also support with the facilitation of a circle of support (13%) (Appendix D. Table 10). Through a mix of learning, follow up and development of leadership skills, people and their families grew in their confidence and extended their networks of support (for example stories by Simon and his mother Cecily).

Participants said that leadership opportunities and investment were also important to develop their skills and confidence. People with disability and families contributed to capacity-building by sharing their stories and knowledge with other people. Most participants (three quarters) reported sharing information with other people (Appendix D. Table 15). One third of participants said they mentored peers, and one third said they shared their story in writing, at conferences and at other presentations (Appendix D. Table 1, and Monique and Clementine stories). Investing in the leadership of people with disability connected to NACBO organisations helped them to develop skills, change outcomes and raise the visibility of people with disability experiencing genuine inclusion (stories by Randy, Ezra, Sammy).

NACBO organisations prioritised capacity-building in different ways. Some activities were working with people with disability directly. Other ways were through building the capacity of supporters and families, while also keeping the person with disability at the centre. For example, a way to uphold high expectations and support implementation of a person’s goals and preferences was to strengthen long-term relationships of ‘people around the person’, like family members, allies, or friends supporting a person with disability (or natural supports). These long-term relationships were an important resource to advocate for the person.

It’s all about journeying with the individual ... Often it might be family members, but it varies in terms of life stage of a person ... with younger people, it’s more often parental family. We also work with couples or adult people with disability and invest in strengthening natural supporters like siblings or close friends. (NACBO leaders)

Some people with disability connected to NACBO capacity-building in this study had set up a circle of support (16.4% of survey participants Appendix D. Table 14). The Circle of Support was to connect to natural supporters and diverse perspectives, which provided them with a platform for ongoing reflection, input about identifying a person's strengths and interests, prioritisation of ideas, opportunities to challenge limiting expectations and accountability for changing outcomes for the person with disability and a long-term safeguard for the future. Examples of investing in long term relationships were Damian's story of safeguarding the future and Darren's story of shifting outcomes and maintaining accountability with a Circle of Support.

Incremental capacity-building

Darren's mother, Kenia said: Darren and I have been involved with [NACBO organisation] for many years. I attended almost all their offerings, workshops, conferences and other events. Later I attended leadership weekend workshops, I had a young family. And taking out that time, to reflect and review, find one little thing we could change as a family to move ahead the vision for Darren's life were critical during those busy days.

Over a few years, I spent a considerable amount of time not taking any real action. I enjoyed attending the workshops ... but nothing much changed in Darren's life. After one family retreat, organised through our [NACBO organisation], I decided to take *one single* small step, deciding to start a Circle of Support. I looked within our social networks and identified four people in addition to Darren and I. Everyone had a strong connection to him.

Getting the group to meet took us another year! It wasn't so much about time or practical barriers, but my internal fears of loss of control as a parent. It scared me ... the thought that Darren might find a job, move out of home, as a parent you want your child to be safe and well.

It's been eight years since Darren's Circle of Support first met. We have learnt a lot about how to run circles and how to keep them alive. The benefits, ideas, connections that arise from these intentional networks can be profound.

The Circle became a true safety net for Darren and our family. They involve real people who are invested and interested in Darren's life and his wellbeing. They can act as a safeguard. We had different facilitators over the years, they are essential in keeping the group on track, to ensure Darren's interests, ideas or wishes would remain at the centre of the discussions and planning.

The Circle keeps parents and supporters accountable. Once decisions are made by Darren, with the support from his Circle, we had to act on them. For example, we

took Darren out of the day program with nothing else set up, which felt like a big leap of faith!

We learned that the diversity of the group was important. Members with diverse life-experiences, such as younger-aged members, present a real opportunity to challenge biased perceptions or expectations, for example, get parents to think what age-appropriate experiences and risks might be. The Circle helped us break down our fear it might be too risky for Darren to attend work by public transport. It also helps us prioritise and break down the next step.

Other families and people with disability said the Circle of Support gave them a sense of direction and common action, boosted motivation and allowed them to celebrate achievements along the way. They said keeping Circles of Support active was as important as starting them with intention. Relying on external, skilled and paid facilitation was another criterion for success. This was a service provided by some NACBO organisations.

The person at the centre

An essential aspect in NACBO approach to build capacity was keeping the person at the centre of their life. The process emphasised starting from each person's own motivations, preferences and interests to develop personalised goals, social roles, building skills and capacity. This one-person-at-a-time approach was crucial to identifying meaningful and sustainable outcomes. The variety of personalised outcomes are illustrated in the stories of change (Appendix C).

Many families tailored supports to the person's goals and interests by hiring support workers and facilitators to change outcomes (for example, Benjamin, Nina, Simon, Jerry, James, Isabelle, Gabriel). Employing workers for this task facilitated flexibility and choice about support. These families use roles-based recruitment and hired workers who shared similar interests, age, or had specific skills and qualifications the person wanted to obtain. One story was by Benjamin who became a radio presenter and was supported by an industry-insider to develop his skills (Appendix C).

Another part of the process was to take a life course approach. People and families could access the capacity-building they needed, at the time they were ready to engage, or when their situation and life stage changed. The approach acknowledged disability was a lifelong experience, across early childhood, education, employment, social relationships and friendships and community participation. Building capacity was an ongoing process that was never fully completed (Mateo's story of capacity-building, Appendix C).

5.4 Impact of the NACBO collaboration

The NACBO collaboration includes six capacity-building organisations committed to authentic social inclusion for people with disability and their supporters and families. The collaboration facilitated mutual learning across the organisations. Governance and decision making was through the leaders in each organisation, some board members, people with disability and family members. Through various collaborations on projects, staff and leaders from the organisations were in regular contact and worked with the other NACBO organisations. The opportunities for working together provided an opportunity for staff and leaders to challenge ideas and learn from each other. The leaders said:

There is strength [in the Alliance] and the ideas that we get from each other ... bring clarity, and then, drive the outcomes home for people with disability being included in their communities. (NACBO leaders)

Staff on all projects [are] now building networks and strong alliances across the country as part of NACBO ... the quality of the work improves because there's a lot of committed people bringing their ideas to the table. (NACBO leaders)

NACBO brought together knowledge, expertise and approaches to achieve outcomes for people with disability and provide leadership opportunities. The organisations said they held each other accountable to high standards in relation to people with disability living a valued and good life. This accountability enhanced the quality of capacity-building delivered by the NACBO network. Working collaboratively meant they could share the resources and expertise held by specific staff, visiting speakers and presenters. The impact was the network was stronger than its individual parts.

The impact from the collaborative work was visible in the holistic suite of capacity-building activities and topics available to people with disability and their families. Almost half the survey participants (46%) accessed resources and guidance of more than one NACBO organisation (Appendix D. Table 7).

NACBO successfully secured funding for their activities. The six organisations worked locally, but connected nationally, which supported collaborations to secure some government grants. This helped sustain the delivery of capacity-building activities and investment in leadership of people and families. Despite uneven, short-term, and uncertain, access to funding, NACBO has endeavoured to expand its approach nationally and grow momentum. The Alliance required considerable

investment in the process of collaboration, recruitment and training of staff to deliver and facilitate the approach, especially while navigating a changing external environment of policy and funding.

5.5 Managing challenges to the NACBO model of building capacity.

How are the challenges managed for the model of building capacity and skills of people with disability and their families and supporters? How can these be addressed in the future?

The NACBO approach aims to achieve authentic social inclusion and not options that congregate or segregate people with disability. This approach is articulated to explain which activities NACBO organisations are offered and why they are focused on capacity building. The NACBO approach is to invest directly in development of skills, confidence, and leadership of people with disability, families and allies.

The NACBO approach to capacity-building is distinctive in the way that it is committed to the capacity of the person in the context of their family to have high expectations of social inclusion through processes that are person-centred. Delivering this approach presents challenges from people and structures more familiar with alternative approaches. This section addresses the questions about how the various NACBO organisations managed these challenges, particularly about their approach to social inclusion, the capacity of families and capacity-building rather than support services.

Social inclusion

Why does NACBO emphasise authentic social inclusion and not segregated options?

The NACBO approach aims for high expectations and full inclusion of people with disability to counteract the devaluation and segregation of people with disability. This aim created some tensions for some people with disability and their families, who felt unrepresented or challenged by NACBO's focus on full authentic inclusion. Some participants in the interviews and survey commented that NACBO offerings were too narrow and potentially excluded some people and their choices,

I am concerned about your position on special schools and supported workplaces. These both have a place in our society and allow freedom of choice for people with disability. Your approach is very unique, and it is great to see an agency advocating for families and giving choices that may not

otherwise exist. However, it is important to be inclusive of all people with disabilities and their needs, which are catered for by including special schools and classes, and supported work environments. (NACBO survey)

NACBO maintained they were welcoming of anyone wishing to engage and build capacity, however, they also needed to be clear about what they could and could not offer as capacity-building organisations.

People have almost made a choice before they come about whether they want something [other than segregation] but they're not sure what [the other option] is or they're not sure how to go about it ... So, [NACBO] actually is one of the choices on their spectrum, so people choose us because they're seeking something else. (NACBO leaders)

Ways that NACBO reduced possible frictions for families less ready for authentic inclusion were to create environments that were friendly, meeting people and families “where they were at”, nudging them towards alternatives, “even if it is just for one day” (see for example stories by Mandari, Ramona and Bogdan, Tej, Kevin). People with disability and families were supported to take incremental changes in follow up conversations and activities, like working with peer groups.

Meeting people where they're at then, it usually takes a series of conversations to explore what that would look like beyond what the person or family had in mind ... having that conversation acts as an opportunity to go forth whilst giving them lots of information ... understanding where that family member is at, and why their son or daughter is in this situation ... Then slightly edging them a little bit further ... towards a better vision and what that would look like. (NACBO leaders)

NACBO were clear that they worked to build skills and capacity, irrespective of what a person and families' starting point was, while they firmly upheld the shared value of authentic social inclusion. The aim was to provide clarity about the model of capacity-building and vision for people with disability, not attempting to be “everything to everyone”.

A focus on families

Why do some NACBO organisations have a primary focus on families?

All NACBO organisations focused on building the capacity and leadership of people with disability and their families. For some of the NACBO organisations, the primary focus is on families because of people's disability support needs (developmental disability) and the family context for this. Their objective was to raise the voice and

preferences of people with developmental disability. Families and other allies could be a major source of ongoing support and advocacy. The NACBO leaders said:

We are not focusing on families or natural supports for the sake of investing in families ... It is in order to improve the life of the person and [NACBO organisations] deliver this in slightly different ways but consistently. (NACBO staff member)

[This NACBO organisation] focuses mainly on people with developmental disability who are vulnerable to systems and have limited voice. If we didn't focus on families, I don't think as much change would have occurred for people with intellectual disability. Families provide an accepted authority in people's lives; if we invest in them ... to shift their mindset and thinking, then we're building the capacity long term as someone who can stand with the person with disability ... A consequence of investing in their family is that the person's voice is strengthened through it. (NACBO leaders)

Some NACBO organisations worked closely with family members and siblings or friends supporting a person with disability. Several organisations focused broadly on naturally available supports and unpaid people in a person's life who had an ongoing relationship and connection. Several NACBO organisations worked directly with people with disability, building their voice and capacity and linking people with disability with peers, alongside their supporters.

We invest in peer relationships – strengthening the voice and leadership of people with disability through building peer networks and associated activities. (NACBO leaders)

Conflicting family preferences

Some families may be more reluctant to engage in change, for example to support a person to move out of segregated disability accommodation. To manage this tension, NACBO used approaches such as individual follow up, gently nudging and challenging low expectations in personalised conversations and through incremental capacity-building (examples are stories by Bella and Darren).

We don't say to people that's a bad choice to send your person to a segregated program, but how might the person experience what their brother or sister experience, even for one day a week? (NACBO leaders)

Many families will seek out information, then disengage for a while...sometimes months, sometimes years. They will re-engage when they require further input and guidance, or when their circumstances have

changed ... it can also be to get help to manage tensions or differing views within families. (NACBO staff).

People without family support

A second challenge was where people have no families or where family relationships were too disrupted to receive support. In these situations, NACBO invested in siblings, other natural support and potential allies, such as paid support workers who could advocate with the person with disability.

Certainly, there are people who are very much alone ... NACBO in different ways connect with allies and friends and some of those will be workers ... the more that we put that message out the more friends and allies we have stepping forward ... We supported a woman with disability who was very alone and three friends were engaged, they stepped up through an advocacy organisation, and have stayed faithful to the woman for 25 years. They made very creative arrangements so that the woman can live in her own home. (NACBO leaders)

Another approach to building capacity of people with intellectual disability who were less connected was to establish links to services that provide individualised support. (story by Marika). Other NACBO organisations developed tailored approaches to building skills and capacity of socially or geographically isolated communities and people. Examples were with culturally diverse communities and recently arrived migrants, or people with disability and their families not yet connected to supports and peers. Examples were the stories by Bernie, Ramona and her grandfather Bogdan, Wandga, also Karelia.

Focus on capacity-building

What is NACBO's rationale for focusing on capacity-building, rather than service provision?

The third challenge to the NACBO model was to explain why the focus was on capacity-building, rather than delivery of services. The NACBO organisations explanation is two-fold. The separation helps build trust with people with disability and their families by avoiding a perception of conflict of interest about also providing services. For example, capacity building might be restricted to the services an organisation provides or might be a "funnel" to obtain service users. This can in turn make the person dependent on services. Second, NACBO recognises that some values-driven capacity-building organisations take on service provision for various reasons e.g., financial viability. In both situations, NACBO argues that these organisations must take great care to manage any risk or perception of risk of conflict of interest.

What is NACBO's rationale for primarily focusing on building the capacity of people with disability and their families rather than systems?

A related challenge for the NACBO model is to explain why the primary focus is building the capacity of the person and family, with the secondary focus on system change. The NACBO focus on investing in people and families brings more surety to good outcomes for a person and potentially acts as an influence on systems. All the NACBO organisations were concerned with changing outcomes for people with disability. Some organisations also prioritised work aimed at influencing policy and system changes through indirect and direct activity. Such work was critically informed by the work in capacity-building, especially the peer networks.

In general, the NACBO approach was to influence system change indirectly through their investment in the capacity and leadership of people and families. The indirect influence was through people with disability and families leading change in their everyday life. The direct influence was through people with disability, families and NACBO staff representing their achievements and struggles at systems levels (examples of this are the story by Peter, who supported by his work colleague Sabine, advocated to receive funding to live in the community). NACBO leaders said:

The value of the NACBO model is all about change one person at a time ... It's about building the capacity of people and their support networks. We are driving counterculture from the bottom up ... You can't do effective policy development ... without actually knowing what's going on in people's lives ... knowing people, understanding their aspirations and where they're getting thwarted, and what it means for policy.

Change is driven at the grassroots, and that's the way it should be, because then change is driven by the needs of the people, not systems ... We work locally in a grassroots way with people using a range of approaches ... and when we have that opportunity [to influence systems and policy] we represent the issues and the stories of people and families. (NACBO leaders)

An example of system change was some NACBO organisations that worked to influence employment opportunities for people with disability. They took the information they had from the grassroots capacity-building to influence system change about employment barriers.

NACBO action on system change was impacted by its structure and funding. NACBO organisations and the alliance were grant funded. Each grant had its own requirements, restrictions and timeframes. The fractured short-term funding limited the NACBO opportunities at system levels, although this remains a priority for the Alliance, discussed further in the next section.

5.6 Challenges and opportunities for the NACBO alliance

What challenges and opportunities emerged in the NACBO alliance and how can any challenges be resolved?

The NACBO collaboration enhanced each organisation. The alliance was an opportunity to extend shared approaches to capacity-building, which influenced their local and national priorities. Working together gave the alliance members greater scope to influence policy through the voices of people with disability and their families. The organisations worked nationally in a collaborative approach and continued to modify their local approaches. They each developed processes to manage this duality. Working well together as a group and on particular projects took time to establish processes and working relationships. However, the lack of sustained funding, given the series of short-term project funding, presents challenges for NACBO to develop, implement, and sustain strategies for a nationally consistent approach to values-based capacity-building and the associated impact on life chances and service systems.

National approach to capacity-building

The NACBO national structure offered collective learning for the leaders, staff, board and people and families involved in governance and joint projects (for example, Bettina, Karelia, Ezra's stories, Appendix C). "We learn from each other, send staff along ... rather than reproduce the wheel" (NACBO leaders). Working as an Alliance also strengthened their influence on policy because they drew upon the collective voices of people with disability and their families across the country.

The results of the alliance, as a collective, are at a systemic level and at a program level ... it offers knowledge exchange ... enrichment and growth, in relation to taking methodology and the enactment of it ... the ideas and approaches. The second outcome from the collective is in relation to the strength of the alliance that gives ... greater opportunity to [use] voice for influence. (NACBO leaders)

The challenge of working nationally as a collective of organisations was that each organisation required additional processes and time to work out how to work together. The success rate securing some short-term funding meant the NACBO organisations also had to grow, recruiting and training new staff members to increase their capacity to deliver projects.

Working in an alliance is always a lot slower, than when you're doing your own thing. But it's more powerful, it's worth it ... because we've got so many

projects to deliver ... we're very particular with the work that we do, so we have to make sure we get the right staff to actually deliver these projects.
(NACBO leaders)

NACBO faced challenges working together due to differences in location, population density, historical and policy differences, and short-term funding. In particular, working in a collective added logistical challenges in the time required to set up projects, develop new relationships with key stakeholders and gatekeepers, and implement new projects, as well as working out how to work as a collective. Many of these challenges were resolved once the new processes and ways of working were established, bringing subsequent benefits.

Funding sustainability

NACBO successfully secured short term government funding for the alliance and for various ILC projects. The growth in this funding, though temporary, has positively impacted the capacity-building activities of each NACBO agency and resourcing the organisations to work together to influence social change.

However, this momentum, and the corresponding impact, needs more sustained funding. Most funding was for short- term projects (1-3 years) with specific delivery requirements and limitations, and uncertainty of renewal. These uncertainties and restrictions posed challenges to NACBO's investment in long-term capacity- building and leadership development for people with disability and the viability of the organisations. The funding arrangements impacted on staff recruitment and retention, long-term planning, expansion of capacity-building into 'harder to reach' communities and people with disability in closed disability settings, due to the time needed to establish trust and relationships with local stakeholders. It also restricted the breadth of the work in relation to addressing capacity-building work towards unfunded projects.

6 Lessons for future capacity-building policy

6.1 Summary of effectiveness of NACBO approach

The NDIS and Australia's Disability Strategy (ADS) rely on capacity-building to fulfil the rights and achieve the life outcomes of people with disability. These policies are intended to form an inclusive society and a sustainable disability support system. The ADS outcome areas are inclusive communities, protection of rights, economic participation and security, personal and community support, learning and skills, health and wellbeing, as well as the seventh overarching outcome of community attitude change. The NDIS is part of the ADS strategy to achieve the goals of social and economic participation, choice and control of people who need additional support services. NDIS is founded on capacity-building to ensure its sustainability by investing in people's social connections and other support services.

The NACBO approach to capacity-building aims to contribute to the sustainability of the NDIS by focusing on people taking up ordinary opportunities (valued roles) in daily life. The approach addresses the risk of the perception the NDIS is the primary provider of all support throughout a person's life.

NACBO process

The NACBO approach to capacity-building is to implement three processes of learning, follow-up and leadership to form high expectations that lead to social and economic contribution, leadership and control (Figure 1.1 and 1.2). These capacity-building activities and principles focus on the person at the centre, in the context of their family. The engagement with people with disability and their families in these processes indirectly and directly influence change in opportunities and inclusion in the community, society and the economy.

The three processes in the NACBO model were effective in developing capacity of people and their families and changing outcomes. People engaged in learning and information through stories from peers that raised their own expectations. Follow up activities were personalised conversations, mentoring, networks of supporters and peers.

NACBO encouraged people and families to become leaders as they gained skills and experience. Leadership roles were within and outside NACBO organisations. NACBO offered a range of paid and voluntary roles and opportunities for people with disability and families. This investment in leadership raised visibility and opportunities for growth, raised expectations for people with disability, and contributed to building the capacity of peers.

NACBO impact and outcomes

People with disability and their families who engaged with NACBO capacity-building experienced a range of impacts, such as connection to other people, to information and resources, and to organisations that could offer support and encouragement. Greater confidence, personal growth, leadership, and self-direction were other key impacts from involvement in capacity-building.

NACBO capacity-building increased people's and family skills, knowledge, and confidence to make changes in life. The approach shifted their expectations and mindsets. Holding higher expectations, exploring possibilities, and creating tailored opportunities for people with disability to live a good life, were starting points to change and sustain outcomes for people with disability.

Their outcomes gradually changed as they formed high expectations, built their skills, knowledge, and confidence, and tried out new experiences. These outcomes were across all life domains, over the life course, as summarised in Australia's Disability Strategy. Outcomes in one area were often linked to outcomes in other areas of a good life. Outcomes reflected people's preferences and situations.

Many people who shared their stories for this study gained self-direction and a sense of belonging in their community. They were known and had relationships and connections with other people; lived in a home of their choice; held leadership in their own daily life. They made a wide range of economic and social contributions, had relationships, income and greater financial security, and were a valued member of their community.

Achieving and sustaining long-term outcomes for people with disability required ongoing attention to building capacity and confidence in people and families. These outcomes included maintaining meaningful open employment, having greater say and leadership in life, new friendships and community connections. People and families benefited from remaining connected to NACBO organisations to address new challenges across the life course.

NACBO collaboration

A benefit of the national collaboration was to strengthen a broad voice of people and their families to influence system and policy change. This activity is built from the personal capacity-building with people and their families. The influence was when people, families or NACBO staff presented their stories outside the NACBO organisations to demonstrate outcomes or address barriers. Constraints on activities to influence system change were the short-term project funding, uncertainty of ILC funding and time.

Opportunities for capacity-building

NACBO organisations were responding to new opportunities for capacity-building, which are relevant to other capacity-building organisations.

People with disability leading capacity-building with their peers

The NACBO organisations applied a range of leadership opportunities for people with disability as peers, facilitators, staff and sharing their stories. Future capacity-building is likely to extend this approach to position people with disability in leading the design, implementation and evaluation of future capacity-building, including influencing policy and system change.

Capacity-building with diverse participants

NACBO organisations vary in the degree to which they focus on diverse participants, depending on their history, size and resources. Historically, the model tends to facilitate capacity-building for people with more social capacity. Some groups were underrepresented (e.g., people living in congregate settings, from linguistically and culturally diverse backgrounds or with complex-interconnected needs). Reasons included the resourcing and time needed to apply the NACBO capacity-building model to these groups, who likely require sustained capacity-building support over a long period and a range of adaptations e.g., interpreters.

The NACBO organisations had various ways to manage their local constraints on addressing the needs of diverse groups. Some NACBO organisations had projects working with diverse groups, including people with disability from culturally and linguistically diverse backgrounds and people without family support. Other NACBO organisations partnered with advocacy groups to lobby the government to fund tailored capacity-building for people in congregate settings. Future considerations might include applying an equity lens to future project activities to prioritise inclusion of under-represented groups.

6.2 Lessons for future capacity-building policy and practice

Elements of effective capacity-building for future government policy and organisational practices

The experience and achievements of people with disability and their families through their connections with the NACBO model of capacity-building hold important lessons for the future of capacity-building in Australia.

The evidence of the effectiveness of the NACBO approach to capacity-building summarised in Section 6.1 has several key elements that can inform the growth of good practice of capacity-building in government policy and organisational practice:

1. **Principles.** The principles and rights to authentic inclusion in the community are embedded in the processes and life outcomes of capacity-building.
2. **Person at the centre.** Capacity-building prioritises the person's motivations and preferences, understanding their changing situation, interests and goals.
3. **Across the life course.** Capacity-building is a lifelong process. It takes time to address new goals and overcome challenges that change over a lifetime. People choose from a range of capacity-building options according to what is most useful at the time.
4. **Holistic and interconnected.** Capacity-building equips the person and their networks of support (families, allies and friends) to lead change according to the person's preferences. Information and resources are linked to activity that builds high expectations, follow up, leadership opportunities and networks of peers.
5. **Leadership.** Investing in intentional leadership of people with disability and families can have an impact on personal and community development, as well as peer learning and sustainability. Effective leadership can also drive positive change in systems and policies.
6. **Long term outcomes.** Achieving success in capacity-building requires taking incremental steps towards long-term outcomes. Maintaining ongoing connections with capacity-building organisations and networks is important in order to meet high expectations.

References

Australian Government Department of Social Services (2021) Australia's National Disability Strategy 2021-2031, <https://www.disabilitygateway.gov.au/document/3106>

Genera, S., Fisher, K. R., Robinson, S., Bellon, M. (2021). NACBO Research Plan, Sydney: Social Policy Research Centre, UNSW Sydney.

Independent Advisory Council (2015) Capacity-building for People with Disability, their families and Carers, Independent Advisory Council to the NDIS, www.ndis-iac.com.au

Kendrick, M.J. (2011) Mobility as a means to an end: acquiring socially valued roles. *Vision Rehabilitation International*, 4 (1) 48-53 DOI: <https://doi.org/10.21307/ijom-2011-005>

Kendrick, M., Ward, M., & Chenoweth, L. (2017). Australia's national disability insurance scheme: looking back to shape the future. *Disability & society*, 32(9), 1333-1350.

Tune, David (2019) Review of the National Disability Insurance Scheme ACT 2013, prepared for the Minister for the National Disability Insurance Scheme, Canberra https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

Wolfensberger, W. (2013) *A Brief Introduction to Social Role Valorization*, Ed 4. NY: Valor Press

UN General Assembly (2006) Convention on the Rights of Persons with Disabilities (UNCRPD). Treaty Series, 2515, 3. United Nations.

Appendix A. Description of NACBO activities

The activities are driven by NACBO principles and offer a multi layered strategy as people learn and absorb information through different activities/resources and over time. See Section 1, 2 and Figure 1.1.

Information and learning

Workshops and Webinars

Workshops in person and webinars online are the main formats for conveying information and educational content to the diverse participant groups. Workshops and webinars differ in scope and duration, some lasting two hours, and others spread out as a series over a few weeks or months. Some workshops are also delivered as a full day event with breaks and catering provided. Commonly they are targeted to a particular group, for example, family supporters, but remain open to people with disability or relevant professionals who wish to attend. Specific workshops and webinars are exclusively tailored to a single audience, for example, a webinar on supported decision making for people with intellectual disability.

Workshops and webinars use a range of engaging tools with a variety of inputs (film, lived experience story, workbooks) and interactive elements where participants work through the information and apply it (case scenarios) together. Local, national and international guest speakers are invited to speak and answer questions. A feature of these education events are co-presenters and guest speakers with lived experience, and people with disability presenting together with their family or themselves. Other speakers include academics, practitioners, industry experts, business development, and Local Area Coordinators. Many workshops and webinars are offered at no cost, others incur a small registration fee.

Conferences and community events

Conferences and conference-like community events are another form of NACBO capacity-building projects. Conferences occur in person, more recently also virtually, across two or more days. These events are a platform for deeper learning to occur, relationships to be developed and for people with disability and family members with lived experience to showcase their achievements and leadership. The conferences are open to the public and are intended to bring together a broad audience including allies and professionals in the sector. For example, NACBO is planning two conferences in 2022, one on open employment and another on community belonging

and relationships. Another organisation collaborated on an event about innovative employment, human rights and growing leadership of people with disability, in addition to showcasing a wide range of micro-businesses and enterprises led, developed, and managed by people with disability.

Multi-day workshops and courses

As part of the ongoing investment in leadership of people with disability and families and to 'dive deeper' into workshop content, NACBO offer tailored longer courses and retreats. These can occur over a weekend and can involve entire families including children with and without disability. The objective of these in-depth events is to foster a sense of community and enable people with disability and family members to engage deeper in specific topics that are relevant to their individual journey to creating a good life with the person with disability.

Resources

Access to resources and information play a critical role in raising expectations and capacity-building. Some of the projects focus on resource development. In several projects, the NACBO organisations partner together to design and develop a suite of websites with relevant, interconnected information, guidance and practical tools to help with the implementation, links, videos, podcasts and workbooks. In addition, each of the NACBO members have their own websites with information and regularly develop factsheets, video and film, podcasts, other written resources (books). These offer people and families alternative access to information at a time convenient for them.

Engagement and new developments

NACBO uses social media platforms, newsletters, discussion groups and other community events to keep people and families connected, informed and interested in new upcoming information and capacity-building events. A couple of NACBO organisations have a fee-based subscription service delivering newsletters, workshops, networking, also video material for workers and professionals.

Follow up and mentoring.

Individual conversations and follow up

The second component of capacity-building is tailored follow up and mentoring to assist people and their families to have individual conversations about their aspirations and goals for an inclusive life. Most NACBO members have dedicated

staff to provide personalised guidance, mentoring, tips or connection with other supports like peer groups and facilitation. This is often crucial in translating learnings and implementing change on a personal level. It also enables people to create change at their own pace.

Peer-based groups and networks

Peer groups and peer networks are an essential form of follow up and support in the NACBO model. The groups are often facilitated by project staff, some are peer-led, with members of the group self-directing. Staff and peer-leaders/facilitators place attention on establishing and facilitating the groups in ways that meet that groups' specific objectives. For example, a group of participants who attended workshops about people with disability living in their own home continue to meet regularly as a group, mentor each other and stretch each other's thinking, also provide mutual support. In one NACBO organisation, peer facilitators of over 13 peer-to-peer networks are supported through education, guidance and support in monthly Facilitator Training meetings.

Facilitations: Circles of Support and discovery meetings

Facilitations can include discovery meetings and Circles of Support. A Circle of Support is a group of unpaid people, informal supporters, friends and allies of a person with intellectual disability, who work together to contribute to the person's wellbeing and vision towards an inclusive life. The groups empower people, assisting them to identify their interests and goals, enact them and safeguard their future rights. Some NACBO organisations have trained staff to facilitate Circles of Support. Most of the organisations facilitate discovery meetings used in employment or home developments to identify a customised plan for employment or steps towards finding a place to call home.

Community projects

Community projects are tailored to deliver specific capacity-building with groups in the community. One example is a NACBO organisation working with a network of Rotary members to develop their members' capacity, connections and employment opportunities for people with disability.

Leadership development and opportunities

The NACBO model invests in the leadership of people and their allies, through deliberate skill building, mentoring and providing a diverse range of opportunities for

leadership in projects (paid employment, co-design) and through the activities they deliver (co-presentation).

Sharing stories and co-presentation

People with disability and their families are encouraged, supported and guided to develop, share and present their lived experience stories through videos, podcasts and written versions. They also share these strengths-based stories in person at workshops, conferences, community events/projects or in peer-based groups. They are encouraged to co-present at workshops, conferences and other events. Sharing lived experience stories was regarded as a way of sharing what is possible, shifting mindsets about disability, raising expectations for people with disability and creating real-life stories with ideas of how change was possible. Stories shared by people with disability and families create a degree of authenticity with peers.

Mentoring or educating others formally and informally

Mentoring peers and providing education to other community members is actively nurtured by NACBO organisations. The model relies on people and families with lived experience participating in peer groups, conferences and other events, sharing their story. They provide practical information, tips, and advice through perspectives from their lived experience. Educating others, building local communities' capacity for inclusion, can also be more formalised. For example, parents might initiate a Parent and Citizen Diversity and Inclusion group at their local school to support the voices of families with children with disability.

Co-design and policy work

Co-design is about designing projects, workshops, activities and content with target groups. Co-design is a process that is applied in some or all parts of a project, from inception and design to delivery and evaluation. Co-design challenges the imbalance of power held by people who make decisions about others. Policy work includes the involvement of people with lived experience in research, inclusion on boards and other decision making groups. The NACBO boards are people with lived experience. One NACBO organisation has established a Co-Design Council of six members representing a diverse range of lived experience of disability. This group brings high level consultation expertise to advise government and private sectors on accessibility and inclusion.

Appendix B. Participation in activities 2020-21

The range of NACBO capacity-building activities are described in more detail, using select examples from the organisations in this appendix as an overview of the number of activities delivered by NACBO in 2020-2021 across the three areas: Information and learning; follow-up and mentoring; and leadership development and opportunities, and number of people and family members participating.

Table 2 below describes the NACBO activities in 2020-2021. It is important to note that numbers were affected by the COVID-19 pandemic. In this timeframe, NACBO delivered 227 workshops to 2,684 participants, people with disability, family members and professionals and 141 webinars to over 5,500 participants between 2020 to 2021. NACBO hosted and organised three conferences in this period. Combined, over 150 000 users accessed websites and online resources. NACBO delivered in total 2,400 one-to-one follow up and mentoring occasions to people and families (1975 occasions), and a smaller number to professionals seeking advice (429 occasions to 118 professionals).

At least 130 people with disability and their family members presented or shared their story at conferences, workshops, peer network meetings and through developing video material. The NACBO leadership development approach also aims to create opportunities for people with disability and family members to be leaders on policy and topics affecting their lives and to be involved in their local communities.

In 2020-2021, NACBO organised 24 inclusive community projects for example, art and cultural exhibitions and markets, events to showcase micro-enterprises, and projects to develop employment partnerships with employers (for example, councils, Rotary club).

NACBO program activities 2020-2021

NACBO activities in 2020 and 2021			
Program area	Activity	Delivered, distributed	Participants
Information and learning	Workshops	227	2684
	Webinars	141	5547
	Conferences	3	634 *attendees available only for one conference
	Peer networks/groups	427	1293
	Presentations and Discussions	28	996
	Website views		151 791
	Resources, publications, factsheets	15608	
	Newsletters	13	
	Videos and podcasts (developed)	1 video documentary 66 video presentations 7 podcasts	-
Follow up Facilitations	One to one follow up coaching/mentoring people with disability and families	1975 (occasions)	n/a
	Mentoring of Professionals	429 (occasions)	118 professionals
	Facilitations, Circles of Support, Discovery meeting, planning meetings Community projects e.g., Employment Partnership with Rotary; Community Gardening; Colourful Cultures Art Exhibition and markets; Collaboration with Australian Coalition for Inclusive Education	1530 24	n/a n/a
Leadership Development and Opportunities	Leadership events and development	14	279
	Sponsorships (to attend events, interstate and overseas travel etc)	29	
	Advisory committees/steering groups	6	
	People/families educating others (presenting stories at conferences, peer mentoring etc.)	-	130
	Policy work – e.g., Disability Royal Commission inquiry, national and state Gov and agencies policy dialogue and inquiries, research, accessibility toolkits, Co-design Guide.	48	

Appendix C. Stories of change

The stories of change are ordered alphabetically by the changed name of each storyteller. Excerpts from the stories are included in the main text of the report.

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Arthur – Building family capacity, keeping the person at the centre

Keeping the person at the centre

Arthur, who has intellectual disability and mental ill-health, had tried four types of housing in the community. All independent living arrangements had failed after some time.

Arthurs' mother reached out to a NACBO organisation for information and advice. She was at a point where she felt that maybe a group home was going to be the only thing that would work for Arthur.

The NACBO member organisation staff took a strengths-based focus in working with Arthur and his mother, looking for practical opportunities to resolve the problems that were causing Arthur's housing instability. Staff focused on how to implement NACBO principles, "that with the right support everyone can live in the community."

Arthur, his mother and NACBO identified that Arthur's moods and behaviours were influenced by access to consistent allied health support. When there were gaps in his funding and therefore supports, Arthur did not receive the right support. At these times his living arrangements were at risk.

The NACBO support helped Arthur's mother to formulate these insights more clearly in Arthur's next funding plan review. Today, Arthur lives in his home in the community.

He feels much more content and supported, he is developing new relationships and interests.

Bella – Moving into my home after 47 years in a closed setting

Bella's story of moving out of an institution to live in her home is told by Eve, her sister

Bella, my sister and I are from a large family. When Bella turned 12 years old my parents decided she would be better cared for in a closed institution for people with disability. Bella lived in the same institution for 47 years. In 2014, Bella moved to a home close to where I live with my family. I manage and coordinate a number of support workers to ensure Bella can live a good life in the community, has more choice about the support she receives, the daily activities she does, and to connect to her community.

The transition to an ordinary life took many years (close to 7) from the day I first connected with NACBO [name organisation]. I attended many workshops and peer groups, had many follow up conversations with wonderful workers at [NACBO]. They were crucial in helping me to develop a vision for Bella's living an ordinary and life centred around her interests and strengths with fewer restrictive practices because her support is managed around her needs to be active and engaged.

NACBO staff were instrumental to our planning, what we need to consider for Bella to live well supported and safely in the community. They helped me manage and find strategies to get support or counter the 'nay-sayers' in my family. Not all my siblings felt the same way, some wanted Bella to stay where she had been, and were reluctant about my decision and wish to create a better life for Bella. Over the two years of intensive planning, I had many individual conversations with NACBO [name] (this was pre NDIS) to work out how to access Bella's funding so we could use it to employ workers in the community, set up operational agreements, shift cycles, Bella requires 24/7 support to live in her home. Chipping away in small steps at the many tasks and decisions, considerations, and planning in those early days.

As my parents were ageing, I took over the nominee role from my parents. The succession planning was complex too, as not all my siblings agreed to Bella's move to the community into her own home. They were weary about any changes or what they would mean for them personally. Today, I am Bella's main supporter and coordinate her NDIS funding, recruit, guide and monitor, and manage the support workers. It is a huge responsibility, and I am hoping one day soon, I can train a support coordinator to take on this role from me, so I can gradually become more a sister to Bella.

The close to 7 years of planning, learning and investment in my skills, in visioning and working towards an alternative means that with the support from NACBO we have now achieved an ordinary life for my sister. Bella's quality of life has improved significantly. She now has choice over important things like: where she lives, with

whom she lives, who supports her, the types of activities and daily living she gets to be involved in – all that has changed. Bella, enjoys gardening, she also sells small plants on a social platform, she regularly attends Karaoke with me and my friends, or with support. We make sure Bella has different opportunities to take part in social and community life.

My leadership is demonstrated in the learning and skills I have developed over the years, also in managing and coordinating Bella's support. Living in a regional community means that when we get out and about, we speak to other people in the community, or people speak to Bella and I to find out more 'how we did achieve this good life'. Recently our family GP asked me to speak and answer a few questions from a young family with a child with disability. To point them in the direction of resources, peer networks, organisations such as NACBO who provided these for us and kept on following up with us through individualised conversations.

Benjamin – Creating environments for success

Benjamin's story is told by Melissa, his mother

Benjamin is a creative young man in his early 20s. He enjoys writing stories, making film and video, and drama. Benjamin loves being social and learning from peers his age. He lives with autism and is aspiring to a career in film, or screen writing.

Before we heard about [NACBO] we were involved with Autism ACT, we tried to set up a small group for young people with autism as there were no suitable or individualised options out there. Around that time the NDIS was rolled out, Ben was eligible. In 2013 I attended a [NACBO] conference on Belonging. This was a real eye-opener... a mind-blowing experience! It changed my thinking about what was possible, creating individualised lives and how we, as a family could support Benjamin to pursue his interests. The speakers were other families and people with disability, they spoke about people moving into their own home or finding open employment. Hearing real life experiences and stories gave me a big motivational push!

First thing, we applied to self-manage Benjamin's NDIS funds to have more choice, enable him to use the funds in a way that best suited his career aspirations, for example by choosing who we employed as his mentors (paid workers). In a short time, I used NACBO resources, workshops and peer groups to learn everything about budgeting, accounting, recruitment, the selection and hiring paid workers.

During his high school education Ben wanted to undertake an internship at a local radio station. Because he loved the experience, we continued and set up an ongoing role for Benjamin at the radio. We designed an individualised work placement. Knowing that Ben finds it most challenging to orient himself in a new social environment, when we created the ongoing role, we asked the supervisor he already knew (from his successful internship) to be his paid mentor. We used NDIS funds to pay half a day of Ramona's time to have personalised support to learn the tricks of the radio trade. Benjamin was eager to learn and felt confident as he was with people he knew and trusted.

Benjamin learnt everything he needed to run and host a radio show. He remained involved for over 4 years (2016-2020), until moving interstate to attend university. This was the first most powerful thing we did the funding. It was only possible because of the [NACBO] inspiration and stories, tools and resources, ongoing encouragement and guidance, including how to self-manage and recruit mentors, and how to build on 'naturally available' supports, like the radio manager. Intentionally customising and creating an environment of success for Ben.

Benjamin building skills, personal growth and confidence

As a result of the radio placement and work, Benjamin developed numerous new skills beyond running a radio show. Prior to Benjamin starting his radio journey, he was reluctant to take the bus. But as he was eager to learn and be involved with the radio, he was more motivated and later took the bus himself. Benjamin developed friendships which have lasted beyond his involvement with the radio station and grew in his artistic confidence.

Incremental steps and experiences to a career in arts and media

The radio involvement confirmed Benjamin's interest in media and storytelling. After high school he took a TAFE media course. We found that Ben was more interested in practical skills, rather than study-based ones. We looked and found a small media production company and hired a young local film maker, Tom, who became Ben's job mentor. For 3-6 hours weekly they worked together under guidance of the media production company to develop video content.

It turned out that Ben and his mentor got along really well. Benjamin wrote the script and story and Tom supporting him to make a stop animation short film. They submitted the film to an ability focused festival where Benjamin won the award for Best Screen script. Importantly, Benjamin and Tom didn't 'cut any corners' they developed the film and work to industry standards. Which further grew Ben's confidence in his creative skills.

As a result of this positive, enriching experience Ben decided to take his screenwriting skills further and study at university. Throughout his university Ben was supported by a mentor he knew through his previous roles and work in media arts. His mentor remains on the lookout for paid roles and projects, while supporting Ben in his study.

Environments for success and leadership opportunities

Benjamin is proud of his achievements. He has presented and talked about his Radio internship for a NACBO resource [video] and presented his short film publicly. I have shared our story and my experience of leading at different NACBO events and am a representative on their board.

A major learning, we take from NACBO is about valuing and honouring a persons' genuine motivation and interests. In practice this meant: remaining open to new or different ideas and opportunities; reviewing and changing what we do regularly; reflecting how to best support Ben in ways that empower him (what skills he needs to develop his creativity and self-direction), ensuring he takes the lead on his projects; and creating environments for success (e.g., use paid mentors Ben connects with or knows, people who share characteristics like passion/interests or age, or are 'industry insiders', staff embedded in the respective business or organisation).

Building a successful career in arts and media requires ongoing investment. Currently we are learning more about customised employment and how to impart this knowledge and skills to Ben's job mentors, as a team and family we remain open to Ben's ideas and motivations, as they change over time and through new experiences.

Bernie - A sense of belonging and making connections

Bernie's story of connecting with peers is told by a Peer Group facilitator.

Bernie is in his early 20s and recently learned that he lives with an intellectual disability. He only just starting to interact with services and to understand his rights. In the past, Bernie had been bullied and treated poorly due to his differences and lack of literacy.

Prior to joining a regional self-advocacy workshop series, Bernie was couch surfing with his girlfriend. When we met Bernie, he was angry about his situation, not having a place of his own, and felt he was not being supported. He also felt excluded by his peers. One of the services Bernie was involved with heard about the workshops series and suggested he should attend to meet new people and build his capacity.

At the start of the workshops, Bernie was quiet and did not interact unless directly spoken to. By the end of the series, a month later, Bernie was a vocal and talkative member of the group. He happily shared his thoughts with the group and was prepared to put forward his ideas, even if they may be slightly controversial.

Being part of the group has helped Bernie find his voice, understand more about his rights, and know where to get support. Less than a year later, Bernie is living in a unit with his partner and daughter and seems genuinely happy. He brought along his baby daughter to a couple of workshops and was proud to introduce her to the group. Bernie enjoys sharing his experiences with applying for jobs and his future plans.

Bernie has formed new connections with several members of the group, and has continued those connections outside of the workshop meetings. Bernie is finding his place in the world and connecting with genuine peers he can relate to and enjoys spending time with, who also appreciate him for who he is.

Becoming part of the group and workshop series has helped Bernie recognise his strengths. While the other services involved have contributed to finding a suitable home for Bernie, and the support he and his family needed, Bernie found connections with peers through the workshops and increased his confidence and sense of inclusion in the community.

Bettina – Leadership and innovation

This story is told by Bettina, an employee with disability

I started working for a NACBO organisation in 2019, as the project lead for an ILC project. It was a pretty challenging time, as no sooner had I assembled the respective project teams, then we were hit with the Covid 19 pandemic.

I am a woman with multiple disabilities, all of which are invisible. I most openly identify as neurodivergent (I'm Autistic and have ADHD). Both of these diagnoses have been obtained later in life, however I have always known they existed. I also have a chronic pain condition and mental health conditions.

My key priority in building the project teams was to employ as many people with disability as I could, and if they were not people with a disability, they had to be someone who supported a person with a disability. I think this was a major contributor to the success of the project, as we understood the importance of true co-design, and involved the people we worked alongside at every stage of the design and implementation process.

I am incredibly proud of what we, as a team, have delivered for my community.

I also want to talk about the impact of my work, my various roles, on me personally. I have always held a goal of holding a leadership position, and the Project Lead role gave me exactly that. I had almost complete freedom to use my out of the box thought processes to identify issues and work to solve them. I was also able to work flexibly, allowing me to pursue my own individual advocacy work.

Perhaps the greatest change occurred this year when I was able to work with the CEO to customise a role that absolutely supports the strengths that I have and gives me the chance to take a break when I need to. As the Stakeholder and Partnerships Lead, I am able to pursue opportunities to make real change, and build partnerships to make it happen. This enables me to use my external networks also to build opportunities for the people we work for.

I realised at the end of 2021 that for me, being a leader doesn't necessarily mean leading a team. And that has been incredibly freeing to me, I now have the opportunity to pursue innovation without the added pressure that comes with management. And that's made a huge difference to my wellbeing, and my success at work.

Candy – Gaining recognition and making a living as an artist

Candy's story is told by her support worker and mentor Gail

Candy is a self-taught painter and artist. She has been using art to express herself since she was a child. Despite being incredibly talented, Candy had previously difficulty marketing, promoting and selling her art.

In June 2020 Candy commenced with her Micro-enterprise project to promote and sell her art professionally. Since she received guidance with her micro-enterprise her confidence as an artist, and her connections to her local community and the art community more broadly have increased significantly.

Through [name of NACBO organisation], Candy regularly attends the Colourful Cultures and Art Shows and other art exhibitions that they help to organise. Candy has built some incredible friendships with other Microenterprise owners through these high-profile community events.

In July 2021, Candy achieved one of her long time goals, she had her own solo art exhibition with a local art gallery. Her show was held over 4 days. Candy was interviewed and photographed in the lead up to the exhibition and afterwards. She was very proud reading and seeing herself and her artwork featured in a number of local newspapers and websites.

Her solo exhibition was incredibly successful and was attended by a diverse group of community members, many people who had previously no connection to Candy and her art. At the opening night 70 people attended the opening including members of her family and some friends. Over these four days, Candy sold art works worth thousands of dollars. She is planning to use to money to go on a holiday in Australia or overseas.

Candy is very proud of her achievements, the recognition she is receiving, and felt she wanted to give back to the community, also inspire other artists, with and without disability, to believe in themselves. She has delivered several speeches at community events, supported by [name NACBO organisation] and shared her story with attendees.

Christie – Your own home and community

Christie’s story of change is told by her mother Tammy and her support worker Christie is a woman in her 30s who now lives in her own home and participates in her community. Christie likes to visit coffee shops, has a passion for stationary (particularly different types of paper) and watching soccer with her family.

About six years ago Christie’s family purchased her a new unit, and she has now moved into her own first home. Her family have appreciated the extensive support, guidance and strategies provided by [name NACBO organisation]. Christie’s paid workers provide round-the clock support, coordination, behaviour support, network advice and NDIS Plan management. These supports assist Christie to live in the community in her own home, further develop her interests, and explore new social roles and relationships.

Christie’s team of experienced support workers employ a strengths-based approach to help Christie build her skills in communicating her choices, learn to make decisions, access the community and explore new opportunities.

Christie has established relationships with a number of people in her local community such as Matt, who runs the local newsagent, and her neighbours who closely look out for each other.

More recently [name NACBO organisation] was involved in creating a work opportunity for Christie centred around her interests shredding paper and delivering this to pet shops Sadly, her work ended when Covid restrictions started in 2020.

Christie’s mother explains that two years of changing Covid restrictions and rules left a negative impact on Christies’ anxiety and disrupting her carefully established routines. They also impacted on consistency of staffing and undid much of the positive momentum she had achieved in living in her own home and connecting to her local community, as she needed to return to live home for 8 weeks.

Now restrictions have eased, [name NACBO organisation] are supporting Christie to work towards her goals to build a fuller social network: there are plans to establish a new co-designed peer network for young women with intellectual disability, explore resuming work opportunities such as starting her own microenterprise or job carving, and build a focus on her health and nutrition.

Clementine – Family leader

We attended a workshop with a NACBO organisation and our life changed. We listened to a story by another family, it was a very powerful story...inspirational. That was about 15 years ago. [NACBO organisation] has supported us along the way, by creating a group of like-minded families who share this vision of inclusion for people with disability. They helped us to form a vision of a good life and holding high expectations for Ryan, our son. Over the years, I also learned how to advocate for my Ryan's interests and ensure he could achieve his best self in life.

Ryan had a brain injury when he was 9 years old. That's how we got into the disability world. We always wanted him to lead a life that supported his strengths. Ryan attended a mainstream school after leaving school he started work at the local supermarket. He enjoys engaging with the customers and is well known in our community because of his work role.

I strongly believe that Ryan would not have acquired the skills and confidence to apply for a role in retail, if he had not been educated together with his peers. Ryan is so embedded in his community! He is more known in the community than me. That has also become a safeguard for him. Because Ryan attended the local school, works at the local supermarket, he is known and loved by many people it is a safeguard.

Over the years, I attended many workshops as a parent, or a leader, to tell and share our story. I could really see how that was important to the attendees, other families. They don't just want to read things in a book but hear from their peers, other families who have experienced similar things, gone through similar challenges, and learn from our story and how we did it.

NACBO organisation gave me the tools to advocate and speak up on behalf of Ryan. I became a different person! I wasn't like that when Ryan was young. I had five children and when Ryan had the accident ... I learned that there was a lot of pushbacks, a lot of negativity towards families with disability. [NACBO organisation] was a light for us – helping us to create and hold up a strong vision of inclusion. ... Once Ryan was out of school and in work...I had more time, I wanted to give back and show other families that there was another way.

I have not only spoken at workshops and presented, but spoken to politicians. I will also educate the builder who was doing work for us, about the challenges faced by people with disability. I went to speak to my local parliamentarian about changes and cutbacks at schools. Hopefully every time you speak to someone, they will take it seriously they will understand, or put in their weight when it comes to decisions about funding and policies or legislation.

Co-Design Council – Having a say in programs, policy and content that concern us

The story is told by the members of the co-design council and the group facilitator

[NACBO organisation] has a long history of advocating and implementing change for people with disability on systemic, societal and individual levels. The organisation uses co-design groups and principles throughout their projects. Small co-design groups are convened to address specific topics and develop targeted resources on individual projects and to influence the way systems work.

The Co-Design Council (also known as CDC) is a strategic group consisting of 8 members with a wide range of subject expertise, representing a cross section of societal roles, cultural backgrounds, gender and a diverse range of disability. The group commenced in 2020 and are consulted on a wide range of issues affecting people with disability, for example public consultations and hearings for policy and NDIS (Safeguarding Taskforce), and accessibility advice for public services (eg, state water). In addition the group provide detailed guidance and input on the content, scope and focus of capacity-building workshops series developed and delivered by [NACBO] organisation, with regional and rural representation and reach.

The CDC meetings are an inclusive space, using online technology to facilitate meetings when face-to-face meetings haven't been possible. "Having access to technology is absolutely vital for people living with disability...It provides us with the forum to have a voice."

The diversity of experience has been of immense value in the consultation work undertaken, together with the spirit of respect. "We all have different opinions, but it's done in the spirit of respect... It's those diverse collective voices that participate like jigsaw pieces." In addition, members reflect "there is no political agenda as a group. The agenda is to improve life for all and to recognise the value of people. Once we all had that same agenda, we clicked..."

Moving forward, the CDC leader reflects,

I think a piece of work is for this CDC to keep track of where there are ongoing or longer-term co-design initiatives and link people with disability up with each other to learn together with us.

Conny 1. Discovery Meetings: personalised facilitation and exploration

Story told by Conny, a young woman with disability

I love doing many things. I play theatre, animals, going to the gym ... After I finished high school, I didn't know what I wanted to do. I wanted a part-time job. My mum mentioned [NACBO organisation] to me. They sounded kind of cool.

They do this thing ... like they get a bunch of people together that know you, they organise the group to help you find out what you want to do in life.

We talked to [NACBO], we had a couple of meetings with them about work and used my NDIS funding for capacity-building to employ them to run the discovery meeting with us.

Mum always thought I'd be good with children, so maybe childcare. Then [NACBO] organised the discovery meeting, everyone was there, my dad, my brother, mum, a friend, ... then my older brother said, I could become an advocate, because I love to speak about rights!

I didn't even know what that word was ... I thought, "Wow, that's a job?", then I want to do that.

Mum started looking for paid roles for me. So, I can learn skills and learn more about my future job, being an advocate. I did a mental health training course because that is what I am interested in, young people and their health and rights.

Few months later I had three paid advocacy roles!

I get paid to provide my lived experience to organisations that want to make services and policy more inclusive for young people with disability. We also found a group community reference group for Inclusion Australia ... They collect stories from people with disability about their experiences, the information goes to the government to tell them how they can do better.

I am still developing my skills in the advocacy field. I am also working part-time as an educator in after school care which is part of an industry training program.

Conny's mother Tamara added her observation,

The discovery meeting and process was extraordinary! We were 10 to 12 people, our family, some close family friends, and young people, Conny's friend. Everyone got a real buzz out of it. Conny's brother for example he felt really proud for seeing sister receive this individualised, best practice, high quality support to live and create a

good life, was inspiring, hopeful and encouraging. For us as a family there was a sense of getting the very best vision, life for Conny and her life.

Being connected to Imagine More helps you think about, repeatedly question your own biases, why should my daughter be different, doing different things. It helps you think of the typical, age appropriate things that young people should be doing and challenge you to want these for your own child, for Conny to be able to take part in the community. Its life changing!

If we did not have [NACBO organisation] direction, support, information and good company our lives would be very different!

Conny and Tamara 2. Learning to customise work

Tamara, Conny's mother speaks about her experience of learning about work customisation

Conny completed high school about a year ago. Over the last two years we have been involved with NACBO organisation to learn all about employment and supporting Conny to reach her potential.

I started by attending a number of workshops all around employment and finding valued roles, investing in her growing and maintaining her social connections. We paid NACBO to facilitate a discovery process for Conny, one focus that emerged from it was advocacy. The discovery process was great, it brought up lots of secondary ideas for us to look into.

NACBO had connections and ideas; that helped us to find a couple of paid advocacy roles for Conny. We use NDIS funding to pay for an advocacy and social change mentor for 4 hours a week. The mentor supports Conny in her work role, preparing for meetings, reviewing easy read versions of documents. We were invited to present and prepared two videos for their Conference, Conny and I talk about what we have learnt from our journey on exploring employment.

About 6 months ago, I joined a peer group called "Going Deeper" that was originally facilitated by NACBO organisation, but more recently is facilitated and organised by the group. The peer group is made up of parents with children who have recently completed high school, to learn more about customised employment and how to do that. The group meets every 4-6 weeks. I have found it incredibly valuable. We gradually know each others stories. There is a great wealth of knowledge and ideas in there, and parents bring questions to the group. I learned a lot from the peers

about how to recruit and set up customised employment support for the young person.

Its about shaping paid mentors or support workers, to help them to understand that they are not there to keep the person company, they are there to build skills, to identify how the person with disability responds to taking on gradually more responsibility, to help them grow and reach their potential. As a parent, I learn in the peer group how to do it, how to recruit, train and monitor paid mentors [workers], so they have the understanding and skills to do their role well. NACBO have also set up a peer group only for paid support mentors working in the customised employment method, so they can connect with and learn from each other. They receive guidance from an intentionally renowned expert on the subject online.

Learning the methodology and 'how to' of customised employment has been a huge learning curve for us. I feel the investment it is working and making a difference. Conny has started paid work in another area, after school care, and she is getting to right level of input, stimulation and support from her job coach to grow and gradually become more independent in her work role. This opportunity came up because the job coach was proactive, they did the leg work, found centres, interviewed them, looked if they were open to customising a role for Conny. That all occurred before Conny had even stepped a foot in the door.

As a mum and coordinator for Conny's paid mentors and job coaches, I could have not learnt this methodology on my own or put it into practice without the input and learning, and personalised conversation I've had with NACBO. They connected me to the peer group members, the international guest speakers, all this made an enormous difference to learning this procedure, and Conny having the right level of guidance to find and grow at work.

Conny 3. Raising expectations and shifting authority for decisions

Conny's mother Tamara explained how the family gradually shifted greater authority for decisions of future and home, affording Conny opportunities to make decisions and age appropriate risks in her life.

Originally, my husband and I, we had a clear vision of home, we had imagined a co-tenancy model ... a middle aged women living with my daughter Conny part time, a sort of dependent model ... After Conny, my husband and I, started working with [name NACBO] we found out ... hold on, she wants to live with young people her age, possibly her friends, and have a swimming pool.

Those conversations happened in the discovery process, it gave us new ideas and perspectives ... and we developed the concept of working towards moving out of home, sort of trials away from home ... It happens that my close friend lives down the road and is going away, now Conny and her two besties from school who will move together for a trial period, housesitting at our friend's home.

Conny will be able to test out what it is to live away from home and live with her friends, she will also have the support she needs, and we are building her skills around everyday household tasks ... It's a quantum leap from what we originally thought was possible!

A few months later, when we got around to do the house-sitting experience for Conny and her friend from school to live together for 6 weeks, the experience turned out to be a steep learning curve for both of the girls. They had clearly underestimated the amount of tasks to do around the house. Perhaps we as a family needed to put in more support for them.

Also, the both young women found out that they were not as comfortable living together, they had different expectations of how they would socialise and spend time during their time in the house together. [NACBO organisation] they have been a highly useful point of reference and resources for us planning this.

While the trial hasn't all gone as planned, we find it was a valuable experience. We talked about Conny's experience as a family, noted the things she enjoyed and what was difficult, so we can learn from it for the future. Becoming independent is hard for any young person! It takes time to feel confident and comfortable to spend time on your own, for us to understand what level of support is required at what times, it's all a gradual learning experience.

Creating a vision

Creating a Vision through input and guidance from peer

Creating a positive vision alongside a person with disability is a critical aspect to building and safeguarding the good things of life. For many people with disability a life filled with typical experiences and opportunities alongside others in the community is not a certainty unless intentional thinking and planning occurs for family members of people with disability. Much of this is due to the pressure for families to choose specialist responses and programs over normative pathways that most of us experience. When a vision is developed that encapsulates high expectations, the interests and passions of the person and has strong principles on the type of life that the person can strive towards it creates sign posts for the future and guidance in the day to day decision that lead to this.

...having someone to connect with to talk through some of the content, some of the strategies, and examples. Then connected with other people who have actually done this before, resources, ... those sort of conversations can be ongoing sometimes for years. We have more informal peer networks, but also more formal peer networks.

A lot of families hear about the importance of creating a vision however some families find it difficult to develop. Capacity-building in the form of peer networks focused on developing a vision assists with this. Families are supported alongside other family members and led by an experienced family leader who has successfully developed and supported their family member to work towards their vision. Many examples are provided along with key considerations to the development of the vision including how to ensure their loved one is at the centre of a vision for the person's life. Participants in the group are guided to hold high expectations of their family member but also of the people they come into contact with, around how they provide support or do the role, whatever that role is around their family member. In addition, families are offered individual mentoring sessions with the family leader as part of this peer network opportunity. A clear outcome received throughout this network is either the strengthening of a current vision or the development of a vision statement.

Damian Creating a vision for one's life

Damian's mother Pam tells the story of creating a vision for Damian

Damian, my son, was still attending high school when the NDIS started in our area. I was looking for information on the big picture. ... I attended a workshop [name NACBO organisation] and the presenter was brilliant!

The part of the workshop that stayed with me were people's stories of living a better, fuller life! One story was about a person who turned around his disability to his advantage. He lived in a bigger home but didn't have many friends, his communication was a bit slower, and he loved meeting new people. That young man started hiring out rooms to backpackers in his community, who in return for cheaper rent made more effort to speak more slowly. He now has friends he keeps in touch with all over the world! It was a powerful story about how a shift in perspective can make a difference.

I went home inspired thinking, "That is what I want for Damian!"... Because it wasn't how my son was living at the time at home...we had low expectations for Damian, we applied a different lens to him compared to his older siblings. About 12 months later Damian started with his first NDIS plan, we had the resources to support him living his best life, having and creating opportunities for him similar to his older siblings.

One thing that had a huge impact on us was creating a Vision Statement together with Damian. We wrote up the first draft, then had a couple of sessions with NACBO [staff] to solidify and refine it. Since about 11 years ago, that document has become a touch stone for our family. When I am tired, we run out of money, are not sure what to do next, when something hasn't worked out as planned, that's when I go back to the fridge to see that document! It helps me with decision making, reflect on what is it that Damian really wants, how can we make it work, and feeling reassured – we can do this!

Importantly, in crating the Vision document, I have had conversations with my son that I wouldn't have had otherwise! For example, I found out more about what he was thinking about the future, what he dreamed of or wanted Before learning from [NACBO] workshops, I had simply assumed Damian had not considered his future much, I was going to make those decisions for him. But the workshops I attended really changed my perspective. We sat down as a family, and I found out that Damian was thinking about his future, he had dreams, and I had not even realised it!

At that stage, in Damian's life, when we created the vision for his life, he wanted to live with a big group of friends in a big house. He was still in high school at the time. He also wanted to find work and make his living.

Damian – Safeguarding for the future: Circles of Support and Microboards

Pam, Damian's mother told their family story

My husband and I come from a small family ... meaning we don't have many extended family. Starting our journey with NACBO changed things for us. We use the social role valorisation approach to create more opportunities for Damian to socialise and meet people. While I could see that Damian was more social, it was still hard for him to make new friends and maintain these connections. Also, I felt I would one day run out of puff. I wanted a 'brains trust' to help us to support the ideas and life we were setting up for Damian and his future.

The NACBO workshop on Microboards and on Circles of Support were very important for us. I met people at the workshop who are very experienced in micro boards. The facilitator later went on to mentor our family, on how to achieve these things in practice, there is a whole lot of technical detail involved, legal considerations. Now, a few years later, we have a registered microboard. It is a small, incorporated body, it will be directly employing Damian's paid mentors. The Micro board can also apply for grants, own property, ... and we have a constitution. It is set up in a way that it is "harder to be wound up". If my husband or I are hit by a bus tomorrow, there are 6 people who know Damian very well, who are not his family, who do not have financial interest or other conflict of interest, only care for Damian and his wellbeing and achieving his vision of a full life. The board members can change over time.

At the beginning, we started with a Circle of Support for Damian. The speaker from one of the workshops supported us with practical tips and guidance on how to make it happen. When we started we paid for a facilitator (NDIS funds), we didn't have the experience to do it ourselves. I was lucky to have a few people to start with. Their first role was to get to know Damian better. So the idea was to have semi-formal meetings first, about 10 people, they were more like social outings. Time to spend together and for people in the circle to really get to know Damian and who he is, what he likes. Later we had more formal meetings. The circle of support focused on employment and brainstorming ideas how Damian could make new connections and friends.

Damian is now early 20s years old with the Microboard and Damian's Circle of Support we are working on putting his vision of finding employment into reality. So far, he hasn't been able to secure work in an ongoing way. Damian needs predictability and regularity to a level that we have not found an employer willing to create that environment. So, we are exploring starting a micro-business where Damian digitalises' photos and documents, now that everything, all our lives, are

moving online. Once the business is up and running, we have the structure, and business plan, we can change it later... likely Damian's interests will change in 5 years' time, having the business structure will make it easier to adapt later.

Darren – Circles of Support can use incremental steps

Darren's story is told by his mother Kenia.

Darren and I have been involved with [name] NACBO organisation for many years. Darren attended a special education school; he was 20 years old when we went to our first NACBO workshop together. Since hearing the testimonies from families, knowing that there were alternatives, we had hope and a new perspective!

I attended almost all their offerings, workshops, conferences and other events. Later I attended leadership weekend workshops, I had a young family. And taking out that time, to reflect and review, find one little thing we could change as a family to move ahead the vision for Darren's life were critical during those busy days.

However, over a few years, I spent a considerable amount of time not taking any real action. I loved attending workshops...but nothing much changed for Darren or his life. After one family retreat, [organised by a NACBO organisation] I decided to take one single step to start a Circle of Support.

I looked within our social networks and identified four people in addition to Darren and I. Everyone had had a strong connection to Darren.

Getting the group to meet took us another year! It wasn't so much about time or practical barriers, but my internal fears of loss of control as a parent. It scared me... the thought that Darren might find a job, move out of home on his own; as a parent you want your child to be safe and well.

It's been eight years since Darren's Circle of Support first met. We have learnt a lot about the 'how to' run circles and how to keep them alive. The benefits, ideas, connections that arise from these intentional networks can be profound.

In essence we learnt,

The Circle became a 'true safety' net for Darren and our family, they involve real people who are invested and interested in Darren's life, wellbeing. They can act as a safeguard.

We had different facilitators over the years [one through our NACBO organisation], they are essential in keeping the group on 'track'. To ensure Darren's interests, ideas or wishes would remain at the centre of the discussions and planning.

The Circle keeps parents/supporters accountable, once decisions are made by Darren with the support of the circle, we had to act on them. For example, we took Darren out of the day program with nothing else set up, which felt like a big leap of faith.

Diversity and members diverse life-experiences, such as younger-age related members, present a real opportunity to challenge biased perceptions or expectations, for example, get parents to think what age appropriate experiences and risks might be. For example, the circle helped break down my fears that it was too risky for Darren to attend work via public transport.

The meetings bring up a whole lot of ideas, actions, and directions. They also help you prioritise and break down the next steps. Most of the follow up tasks fall on paid support workers, but members of the circle at times contribute as they have distinct connections of their own (e.g., when it's about finding work opportunities).

Circle meetings also provide a sense of direction and common action for the support workers, a boost in motivation and opportunity for celebration when small milestones have been achieved.

Keeping Circles of Support alive is as important as starting them with intention. At times the vision and purpose of a circle needs to be reviewed, or membership refreshed to ensure that the inputs (from members) remain relevant to Darren's life-experiences. For example, we regularly have discussions with Darren about adding new members, when he is very close to someone. Darren gets to decide if someone "only" remains a friend or gets asked to become a "circle member".

Dylan – Building a career as a fitness coach

Dylan’s story for working towards becoming a fitness coach is told by Dylan and his mother, Belinda

“Hi, my name is Dylan. I am a motivated person.

I like doing sports – gym, taekwondo, soccer, hanging out with friends and family – and smashing my goals! I like all of them because it keeps me included in everyday life, it keeps me busy!”

“The best thing about soccer is being supported by the whole team. I have been playing with my team for 11 years. I like it because I get an extra burst of energy. I relax doing sport and that helps me with everything else. “

“If I’m not doing sports, I work as a social media coordinator in a small local business. Every Monday I work there for 4 hours, I like being part of the team, they give me clear tasks and responsibilities. I know what to do and I do it well.”

“The best part of my work is feeling included, being part of a team, and I get money!”

“I go to the gym a couple of times a week. My goals are getting stronger, more energy, and making new friends. I wrote down a few goals for the gym at the start and set a date for when I wanted to achieve them.”

Dylan’s mother, Belinda said:

We have been involved with a number of capacity-building organisations, including [NABCO]. Dylan was quite young when, we started our journey of ‘Thinking Big’. When we received Dylan’s diagnosis we found it disheartening. We soon after found a local capacity-building organisation that helped us to think outside the box.

What NACBO organisation gave us is – ideas – how to view our child as a person, as a valuable human being! Other organisations gave us valuable support (therapy, social services), we also needed a vision for Dylan’s life. Attending conferences and hearing of other parents, a little further on the journey, gave us ideas, strategies, energy, empowerment how to do it.

Dylan had different jobs, all in open employment. Currently he is working at a local media company, we know the business owner. He is also a paid consultant for a community disability advocacy organisation.

During school, Dylan wanted a job. We came up with a fast food outlet. We were lucky to have a friend in a recruitment agency, who rang up the head of cultures and they set us up with a retailers who were open to including Dylan as a staff member.

He worked in a job for a year; he had support to do his job. Then Covid hit and he lost his job. It was a good start, but he didn't make new friends through his work.

In the last couple of years, Dylan is building to develop his confidence in office based work. He found employment through a friend. We are connected to a Cerebral Palsy Disability Employment Service and they supported the business in setting up Dylan's office job. We wanted Dylan to be paid a full wage. His role was carved out, the job description re-written, we chose the tasks that Dylan could do well, so he is regarded as an asset and full member to the business. He attended 4 hours and was paid a full wage. That small business shut, and Dylan lost his employment.

We are working with the DES provider who has connected us with PCYC. Dylan was offered trial work as an assistant, which went really well. If he gets offered the job, he will be working part time in the after school program mentoring teens and children around sports, which is his great passion. Dylan's dream is to become a fitness personal trainer or coach, he is attending TAFE to get his qualifications alongside his work commitments.

Dylan is very much into sports, group and strengths-based sports. The job with PCYC will complement his long term plans!

Ezra – Leadership and driving organisational change by people with disability

My name is Ezra! I am 37 years old.

I live in my own place and will soon have a housemate moving in next weekend. The housemate is moving in for financial reasons, but also for company. It can be a bit lonely living alone... I would love to have a pet one day!

I work for a NACBO organisation. Before this job, I had many other jobs. I worked in child care, I worked as a crossing supervisor. It's been 5 years since I started work for [name NACBO organisation]. I am in an admin assistant role. I am also the organiser of their disability advisory council.

My role with the disability advisory council is to be the organiser, I support the members. For example, I help with the preparation of easy read material, send invitations, set up the meeting, and support people to feel comfortable to speak up.

Last year, I attended a NACBO workshop on supported decision making (for supporters and parents). It was important information and I wanted to share it with others. I wrote up a manifesto called, "How I want to be supported to make decisions". After the workshop, I told [the NACBO manager] that it would be a good idea hold a similar workshop for the advisory council. They council agreed to the idea. Then we invited a guest speaker to come and talk to the members about supported decision making from the perspective of people with intellectual disability. I also presented. I spoke about how I want to be supported in making my decisions. Preparing and presenting for the workshop really helped me to be clear about ...to say...that people can put me in the driver seat, it is my life. And I want to make the choices that I want to make. I felt more confident after it.

Because the presentation to the advisory council went well. The other presenter [from a university] and I were invited to hold the seminar at another group for people with disability. A few months later the NACBO organisation and I were invited to talk on Supported Decision making to an advocacy group. The Participants really liked my presentation.

While I started in an office admin role, now, I also help prepare and am a presenter at seminars, talks and presentations for NACBO and to external organisations. I bring in my voice and the perspective of a person living with intellectual disability and how I want to be supported.

I have grown in my work tasks, and I am enjoying it!

To have work is very important. It allows me to live and rent my own place. Also to save up money to go on a holiday... in a few months' I want to go to a Pink concert!

NACBO manager said:

A reason we started the disability advisory council was that the [NACBO organisation] board felt we were not hearing from people with intellectual disability about what sort of capacity-building they wanted and how we could support their voice. We realised we needed to create a separate and dedicated space to listen to and support the voices of people with intellectual disability as material needs to be understandable and targeted so that it's not tokenistic. We realised we needed to create learning space in which material could be easily understood and we could receive feedback and ideas from people with intellectual disability. It wasn't enough to have a person with an intellectual disability sit at our board meetings, or to hear only from family members. The advisory committee is now more than a representative model and is able to provide much stronger influence internally and externally.

Employing Ezra and building her leadership capacity to present and speak at the supported decision making workshop started off a number of flow on effects for our organisation. Ezra asked for a similar workshop to be created for the disability advisory council, she helped produce the content for the workshop, and has since co-presented the seminar to other audiences and organisations.

All these new activities and developments would not have happened without Ezra's leadership. Employing Ezra, who brings a wealth of lived experience, has enriched and diversified what we do as a NACBO [organisation]!

Family Lead Peer Networks

The development of families that enables their loved ones with disability to experience the many good things of life is the primary focus of our capacity-building work. Investing in families acts as a strong conduit to securing a person with disability rightful place within the community. As the organisation has been investing in building the capacity of families around innovating models of support that has led to authentic inclusion there are many families linked to the organisation that can directly share their experiences and successes with this.

Experienced family leaders facilitating peer networks for less experienced families are a powerful means to build increased knowledge, improve motivation and acts to break down barriers that may exist between families and formal services.

The family led peer networks focused on the following, Positive vision; Self-management; Community connections; Circles of support; Socially valued roles; Employment; Education; and Individualised living arrangements.

As part of a current capacity-building project these family led peer networks are provided with supports from organisational staff. Parameters surrounding the network and what will be covered are set up to ensure that high expectations for inclusion are at the heart of the network. The family facilitators provide content rich information that highlight their own experience as well as the experience of others. This includes working through the barriers that may present when attempting to navigate systems and supports that are not set up to genuinely include people with disability. Families in this respect are often fore warned therefore forearmed to navigate this successfully.

Family Leadership Series

The aim of investing in family leadership is to layer capacity-building and support families to get them to an informed place. They then can contribute in different ways by sharing with their peers and by supporting their loved ones. There are many aspects to the leadership development of families within our capacity-building work with one such example being an extensive six-month leadership series that works towards:

- growing connections, awareness and skills so families can be empowered to take on leadership roles for change in their own family and the wider community.
- Deepen family's knowledge in Social Role Valorisation (SRV) and the importance of holding valued roles to support people with disability to live typical and valued lives.
- Increasing family's skills and capacity to support people with disability to live good lives in the heart of the community.
- Coming together with other passionate families in a safe supportive environment, to exchange ideas, and access the latest resources.
- Build families capacity in advocating for a Good Life (including areas such as education, work, home, building relationships and community inclusion).
- Apply family's skills to share their stories of inclusive within communities and/or within the work of the organisation.

Families are targeted to attend this series once parameters on who the series will target i.e age of person with disability in their lives, geographical location, values and mindset, prior exposure to the work of the organisation. These families have already been identified in multiple ways across the organisation which has led to being placed in our 'Leadership Potential' database. Expression of Interests are sent along with an outline of the series to families. The series is supported by both organisational staff and experienced family leaders who attend the entire series to provide support and insight to the group. The family leaders enlisted to support the newer families must exhibit commitment from both a values position and a practice position and hold as a good example of leadership for families in supporting their loved ones into valued roles within community.

An important aspect to these events is the involvement of participating families post the series. Opportunities are matched to the skills and experience of the family leader and they are given opportunities to feed into other aspects of our capacity-building work. For example, two families from the last series are contributing and involved with the next leadership series, other families have been supported to become a guest speaker at a relevant event, others asked to hold governance or

other roles across the organisation. Support in some of these roles are provided by the organisation as families develop their experience and confidence.

Post Family Leadership Series survey's work to capture increase in knowledge, confidence and motivations for actions all centred on the impact of the person with disability in their life.

Gabriel - Planning for the future

Gabriel's story of living in his home and planning for the future is told by Emma, his mother.

Gabriel is in his 20s, he loves to do art, sculpture, painting, and socialising. We have a big family and Gabriel loves spending time with his family, he also enjoys living in his own home!

I attended the first NACBO workshop over 10 years ago. It was inspiring and daunting. Initially I felt a bit confronted by the ideas of full inclusion. Gabriel had attended a special disability school, he has autism and uses few spoken words. Over the years, I have attended many [name NACBO organisation] workshops, conferences, meetings with other parents... Hearing the testimonials from other families and speaking to others in peer groups left its mark. We realised that Gabriel had a lot to give and there were other opportunities for him in the community.

We are older parents, Gabriel was our last child, until recently he lived at home. We wanted to make sure he could continue living a good life without being dependent on us, we are going into retirement. An important step was to ensure Gabriel did not have to live with other people. He is particular, with his OCD, everything has to be done in a certain way. Gabriel would only be happy and comfortable in a home of his own with the right support in place.

Planning for Gabriel's move and living in his own home took a few years. I had a lot of input and guidance from peer group and parents, also conversations with NACBO and other organisations. We were lucky we found and could purchase an apartment for Gabriel in our local neighbourhood. It is perfectly situated between our home and where is older brother and his family live.

When we applied for NDIS funding for Gabriel to move out and have the support to live alone, we staggered it, so he would be at his new place for 5 days a week, and come home to stay with us on weekends. It's been a year that Gabriel lives in his own home, and he really loves it! When he "has to come home on the weekend", he walks up the stairs to his room and shuts the door. As if to say, "why can't I stay in my own place?".

As a result of the input and learnings through NACBO, years ago we started to self-manage Gabriel's support package. We employ and hire a small group of young support workers he connects with well. We involve Gabriel in the decision about who we hire.

The last few months have been a big step learning curve for all of us, Gabriel, the support team and I who manage his support. Gabriel has his own way of communicating, you can't take many words literally, they are more expressions of an attitude or state of mind. The support team had to learn a lot about Gabriel and who he is, what he likes and doesn't like.

Attending a NACBO event I was inspired to seek out speech therapy for Gabriel. The therapist is now working with all of us - with Gabriel to improve his expressions so he can more easily express his wishes and give directions. The therapist also dedicates sessions to skill up the workers. Spending more time with Gabriel, learning about his communication style, has made a big difference to the quality of his support. This is evident because we have few challenging behaviour incidents, where Gabriel gets too frustrated about not been understood or heard.

Since moving into his own home about a year ago, Gabriel is learning to express his wishes more clearly, his language has improved, he is learning tasks of everyday life. Gabriel is also expanding his social life. Because we have flexibility and choice about who we employ, Gabriel's support team are young, vibrant and of similar age. They come up with fun and interesting things to do in the community, if Gabriel is not busy at work creating and selling his art!

Gabriel would not be living such a full and included, self-directed life, if we had not met NACBO 10 years ago. Possibly, he might have moved to a group home. You don't know, what you don't know, until you go to a few of these workshops, hear stories and get the resources, follow up encouragement to make a change.

Isabelle – Growing my confidence to speak up and skills to self-manage paid support

Isabelle told her experience of gaining confidence to speak up

Isabelle took part in one-to-one mentoring and NACBO workshops and other capacity-building activities. She explained that being involved had greatly increased her confidence to speak up for herself. She felt that she has skills and confidence to manage her supports and navigate the interdependent relationship between herself and her paid supporters. Isabelle told her story.

I felt stressed and anxious, I had to work out how to stay on top of my education and manage my support workers.

At some point, I just couldn't cope anymore. I knew [the NACBO organisation]. I had worked with them in the past. They suggested we do one-on-one consultations, paid through my NDIS plan. Together we worked on building my skills and my confidence to manage my own supports, the people I employ. I knew them from workshops and conferences I attended in the past. I really like how they see the world and their values!

They helped me to work out how to manage the parts I was finding challenging, like setting up boundaries, clear communication, for example, we wrote up a list of "absolute deal breakers", things like passive aggressive communication, pushing boundaries. Then we talked about strategies and put them in place how to communicate them. Every time I experience a new problem, we talk it through and find ways to make it better. I can now stand up for myself, rather than bottling up my feelings inside! But the troubles I had in the beginning did leave a mark, I used to get really angry and sometimes I felt depressed. I wish I could believe in myself more. Managing my support workers is not an easy task, but I know my confidence will grow over time. I am doing one on one consultations with them, when I need to. They really helped me build my skills to have more confidence to manage my own support workers. After one session I already felt so much better, so I asked it to continue. This capacity-building consultation is paid out of my NDIS funding. It's super easy and has been really helpful. After one session I felt so much better, more confident. I asked for it to continue. I knew when I had found my voice, when one day in a class, 'I decided to do something that my support worker would not agree with, he responded in a passive aggressive manner. I stood up for myself.

I am gaining in confidence about how to speak up and know when it is my right to do so. Doing so has made a big impact on my self-esteem. I know now, if I can do that, I can do almost anything in life

James – Securing employment is not a linear achievement, things change over time

James's story of finding work aligning with his interests is told by his mother Kate

I was hungry for information; I wanted knowledge, skills, and to hear other people's stories, to put it all together...I was looking for something different and found [name NACBO] organisation, close to 15 years ago. I saw that families were creating an included life for their family member. I came away wanting the same for James, who was still in primary school then. It made me question James going to a special school.

Over the next years, because of the connection with to [name NACBO organisation] I became involved in a number of disability advocacy organisations. I wanted things to change not only for our family, but for people with intellectual and other disabilities broadly.

James had social connections in his community, we were made aware of the importance solidifying these and grow new relationships. The first thing we did to act on we started James's Circle of Support. The Circle proved to be critical when James completed school, preparing for his life after, when the routines and structures change.

The Circle involved our immediate family, some extended family members, a family friend, a support worker who'd worked with James many years, a young person, James' teacher from school. All members knew and were connected to James. We had a paid facilitator to help the Circle work through what James's skills and interests were, how to match these to work jobs James, then help us find a company seeking these skills. James' older brother is a great networker and he helped to forge the first connection to secure James' first paid employment.

During his employment, we ensured James, who loves being social and connected to other people without using spoken words, had opportunities build relationships at work. We observed James's engagement after a year and found that he was losing interest in his work that's when we held another Circle meeting to plan for another employment opportunity. Through a family friend we managed to connect with another business, a PR company. James had an admin role and ran a wide range of support tasks for the teams. Then Covid happened and he lost this work.

We are currently looking into paid employment for James where he can learn new skills and make connections. We are also getting support from NACBO organisation with an ILO application to set up a home for James. Because James

is very social we are considering a housemate model, where James has paid and informal support to live in his own home.

NACBO has taught us to dream big, use different strategies, stay connected to peers, and to step by step create a typical life for James

Jerry – Transforming a passion into a business

Jerry’s story is told by Nate, Jerry’s long-time paid support worker and ally

Jerry is a vibrant 21-year-old man who has worked with NACBO to develop and build his own lawnmowing and gardening business. Jerry received capacity-building support over three years during various stages of the business development.

Jerry is a loud guy with a great sense of humour, loves commentating the football, and loves a ride-on lawnmower. After leaving school, his family and support worker identified ride-on lawnmowing as a job option and developed ‘Jerry and Nate’s’ lawnmowing adventures’. Supports were initially managed by another organisation, however they couldn’t provide a consistent vehicle on time which upset Jerry’s routines and didn’t work well for him.

In 2020, [NACBO organisation] joined Jerry’s family and allies to help them to advocate for increased NDIS funding and qualify for School Leaver Employment Support (SLES) funding. Once Jerry received the funding, [NACBO organisation] provided creative solutions, strategies and capacity-building. They supported Jerry and his team– to build their skills in developing a business plan, understand and navigate NDIS funding, and apply for small grants for equipment to purchase tools like a whipper snipper and leaf blower. This was a big learning experience for everyone involved.

Since starting his business, Jerry has saved and bought a trailer and a ride-on lawnmower. The next steps for Jerry’s business are to explore employing additional staff to grow his business, refine the business structure, and promote Jerry’s services using marketing and radio advertising.

Jerry’s business and team recently won a state award for excellence in supporting employment outcomes – an achievement for which they are all immensely proud!

Karelia, Building trust and capacity in culturally diverse communities

A project officer with disability reflected on her experience of providing capacity-building to others members of her community with culturally low expectations of disability.

Providing disability awareness workshops to culturally diverse communities has helped shift some cultural and conservative views about disability.

As a former refugee with lived experience of disability, I have gone on to obtain professional qualifications and lead community development. I have seen how it has helped people shift their mindset and expectations.

In many cultures we speak about disability as a taboo, there is shame and stigma attached... But me standing in front of my community as a trained facilitator, a highly educated woman...well, that makes a difference. You can either choose to be sad, or you can choose to live a fulfilling life, like I am doing now. That is the message!

The NACBO approach aims to change expectations one person at a time. We staff regularly observe how the people and families who attended the groups start to have more open conversations in their own communities, those attitudes about disability changing slowly.

It happens through peer network meetings, these are growing with increased attendance, building confidence in people and families about their rights you have when you are or support a family member with disability, that there is no shame attached, and how they can ask for support, they are entitled to it!

As one of the peer group leaders I have personally observed that people who attended the meetings felt more empowered when they felt after a few weeks. Over time, their confidence has built as attendees started to ask more questions, or access services, and express their needs. In the groups people talked about issues such as the process and the system, how it works, their rights of people with disability, and how to seek or ask for an interpreter.

Learning about the NDIS and the system in a culturally responsive approach really builds capacity in these communities, families to support each other, to share the knowledge and information.

Kevin– Marking everyday choices

Kevin told his story of personal growth in making daily decisions and running a small business

I have a passion for sports, Zumba dancing, and riding my push-bike. Twice a week I go to a local gym and am paid to work there. I work at the reception. I also do other jobs around the gym.

A favourite part of my work is getting to and from work [on my bike].

I like the freedom to change what I do and like buying things with my own money. Once I bought the workers near our house some doughnuts. I like watching how they dig up the concrete and the soil.

I also run a small ironing business. I enjoy ironing shirts. I pick up the shirts. I have eight clients. When they call or text, they need my service, I pick up the shirts and when they are done, I deliver them to the client. I go there with my worker. It's a high quality service!

I like my work. I have a business card and an Instagram page. With my business consultant we want to find out how we can grow my business and make it bigger.

Once every two months I get to sit on the [NACBO organisation] advisory board. I listen. I also give them ideas about what people with disability want. My support worker helps me prepare for the meetings.

Kevin's mother, Mona added...

Kevin used to go to special school, was in his final year, and I looked at post school programs. I was disappointed with the quality of services available. Most of them were day programs where people with disability were put together. Kevin was offered a spot in a group together with people double his age! We felt he would be removed from society simply because of his disability.

We didn't find any alternatives, so we selected the program that sounded most diverse. After a year in the day program we chose for Kevin, we found that Kevin's ability to choose what he wanted to do was very limited, there were too many rules set up. None of the activities were about his interests. And Kevin was not "permitted" to cycle there, for "safety" reasons, in case he'd get lost or have an accident on his way there.

We started looking into alternatives and luckily for Kevin and us, we found [name NACBO organisation]. I attended a conference on what families can do to support and ensure people with disability live a good, more self-directed life, based on their interests. Coming out of the workshop we helped Kevin carve out a life, tailored to his interests in his community.

At one of the workshops, I met a young woman, she later became Kevin's mentor. We employed her to support us in designing Kevin's business, identify Kevin's interests and how to create roles and connections from that. We knew Kevin enjoyed the gym and swimming. His mentor searched and found a local gym that was recruiting someone to do small jobs. His mentor established the relationship with the gym and built their capacity and understanding of what Kevin's role could look like, and how the gym could support him in his roles.

Getting tailored advice and guidance from the mentor was extremely important for Kevin's success. The worker/mentor helped Kevin to brush up his skills, to be "job ready". She supported him to do relevant courses (like first aid) by tailoring the information in easy read.

Today, Kevin has a paid job for 2-4 hours a week. He knows most of the staff and is confident when he goes there. He cycles to work on his own. Kevin comes home after work with a smile. The place he works at, also arranged for him another work experience, where he is learning to become an assistant swimming coach! He also runs his own ironing business.

Kevin and Mona – Building supported decision making in people and their supporters

Mona, Kevin's mother, spoke of learning about supported decision making for herself and her son.

Through a local NACBO organisation, Kevin and I, separately attended supported decision making workshops. They have been really helpful in our daily decision making, especially reflecting on how we, Kevin's family can learn to give Kevin more opportunities to take responsibilities, make his own decisions and take age appropriate risks.

I attended a decision-making workshop only for supporters and parents. I help my son with his decisions, but I don't always know if what I am supporting him to choose

is the right choice. It's not always easy to hold back your own ideas of how things should go, your expectations for your child.

I believe I know Kevin really, really well. So, in this workshop learnt how to sort of let him decide more, rather than put too much of myself in his decisions. It's a tricky one.

[name NACBO organisation] has many good events, podcasts and resources, and I have listened to a few of them several times, over and over. They help me stay focused, on what our role is as Kevin's parents, like little reminders to step back little by little, as Kevin is gaining more experiences and growing in confidence as a young man.

Kevin will shortly attend a workshop about supported decision making run by our local NACBO organisation, exclusively for people with intellectual disability. His mentor will support him to come on screen and add a few things, but the aim of the workshop is for Kevin to gain skills and knowledge about voicing how he feels, what he wants, and how to voice these things. He seems to like his role. Attending those sorts of meetings together with his mentor, that really gives him opportunity to express himself more. While, when I am there to support Kevin, well, I am his mum, he tends to look at me for input, getting that indirect approval, if he's said the right thing. It's what any young person does in an unfamiliar social context. We want Kevin to develop his own ideas, and have more opportunity to speak up for himself.

Laila – Finding work I love and am proud of doing

Laila's story of carving out a role and position in aged care is told by the program facilitator

Laila is in her late 20s, and has worked and tried many different jobs. Her last role was cleaning in a hospital, however she did not feel part of a “workplace or a team”. Moving between different jobs and companies has left her feeling isolated and hopeless about her future.

Laila explains how she felt in past jobs, “I wasn't happy, and I had trouble with my communication, I was scared to talk to my co-workers, I felt mute. It is hard with my intellectual disability and with English as a second language. It leads to misunderstanding when I translate for myself, and it feels uneasy”.

Laila decided to participate in a program that ‘carved out’ positions in aged care, although she'd never considered doing this type of work.

From day one, this job felt so different! I felt mature, I started to be active and worked hard. I was also curious to get to know my role and the work as a carer. Today, I feel confident. Because my daily job is to talk to older people, it makes me feel like I have a purpose and an important role. It's a bit like I am talking to my great grandmother...I feel compassion when people tell me about their aches and worries. I care for them with open arms. I am understanding. I love my work!.

Laila has experienced some challenges at work, such as feeling misunderstood by her supervisors and team colleagues. The project worker has supported Laila in different ways, including providing inclusion mentoring to the CEO of the organisation, inclusion training to the work teams, and supporting Laila to develop a resource so she could more easily connect with her supervisors and team. The resource includes tips on, “How to Support Me at Work and How to Bring Out the Best in Me”. The Tips for her supervisors and team colleagues include:

- using simple and clear language for instructions
- asking about her disability and how it may impact on the task at hand
- asking how this impact could be amended/improved/removed
- adding jokes to ‘serious conversations’
- providing regular encouragement and positive feedback

Laila attended the graduation ceremony supported by the Disability Employment Support worker and told her story of moving between jobs not feeling “like she belonged” at any of the places she worked, and “feeling invisible and replaceable”.

Having found work and a career in aged care that she loves, where she feels she can “give back” and make a “real difference” gives her pride and a sense of purpose in her work. Laila also feels more connected with other people as part of her daily work, a core aspect of Laila’s job satisfaction.

Leon – Employing a worker helped me find work I love

Leon told his story of finding and sustaining work in his community

Leon has worked part-time for 17 years at a local small business in a regional town. He rents his own unit. His work, home and volunteering at a farmers' market mean Leon has connections with many neighbours and friends around town who know and respect him. He regularly meets up with them for coffee and shares his love of sport. Leon is also the proud uncle of a niece and nephew. He enjoys spending time with his family members and older brother, he treats them when he visits.

Life was not always like this for Leon. He was isolated, lonely and had nothing to do through the day. He had tried various day programs but found them boring and was underpaid at a disability employment service. His mother attended a session organised by a local government branch. A NACBO organisation's staff member presented at this session and later meet with Leon and his family. This was the beginning of a new and inclusive vision for Leon. With assistance from his family, Leon employed a worker to help him find a paid job he liked.

We had a meeting at Mum and Dad's, and I told [name NACBO organisation's staff member] what I wanted to do. Then we put it in motion. I got a house and I moved to [town] and that's how we got the ball rolling... I love being in [my town] because there's heaps to do. I can go to the movies or my support worker we go to the movies together, to the cricket, too!

Through lots of discussions with the worker, Leon decided he wanted a job around and with other people. When they found the job that met this criterion, with a small local business, Leon completed a 3-month trial and they made worksheets so all the tasks were clear.

When I first started, it was the 3 month trial and in that 3 months was my support worker. [Lydia], she helped me! She did a manual for me with all the instructions that I follow so I can do all my tasks.

Leon has now worked as a receptionist for over 15 years. He likes the people at the business and likes what he does. He does not want to change anything about his work, even when some of the people at the business change over time. Leon has even gone on holiday with the boss, since they share a passion for cricket. Leon has sufficient funding to pay for a housecleaner from his package, since his work and income is so stable.

Moving house three times over the last few years has been stressful. However, Leon loves his current unit and hopes he can stay there long term. He

emphasises the contrast between all he has now, and the problems he experienced before employing a worker, which turned it all around for him.

Leon is also paid as a consultant for the NACBO organisation to represent on an advisory committee.

[On the advisory board] we talk about people with disabilities and work, employers employing people with disabilities. The last meeting was about decision making for people with disabilities, I said, “if people with disabilities, if they want to make decisions and don’t know how to, they could ask their family or friends”. Also, if other people are making decisions for people with the disability, and they didn’t like it, they could tell them how they’re feeling. It is important for people ... it gives them more confidence, it can boost their self-esteem when they make decisions.

Today, Leon feels confident to do these jobs, like being on the advisory board, because he is satisfied with his work, he feels valued and respected at work, in his home life and with his friends. Leon also enjoys telling his story (of finding a home, work, employing a worker) in presentations, videos, on an advisory committee, social media and government consultations, like the Disability Royal Commission. Leon says his work with the NACBO organisation, and his social media profile help other people learn how to make decisions, to have a go, try something different, and build a good life.

Liam – Part of community and forming childhood connections

Liam’s story of inclusive childhood connections is told by his mother Sarah

Liam lives in a regional small town. His mother says that when he was born 13 years ago, all they heard were “negative things”. She had not heard a doctor or medical professional speak in a positive light about Liam and his future possibilities. They have been involved with NACBO over the years and it has profoundly impacted on Liam’s opportunities language and connections, as well as the families’ sense of belonging to their local school and community. His mother told their story.

My son Liam was born with a disability. We attended [NACBO organisation] events and decided we wanted him to go to a mainstream school together with his two older brothers.

People expect the school community to be accepting of a child with disability. It’s just not like that. Prior to having a child with disability, I wasn’t assertive. But coming to the [NACBO organisation] events and seeing other family leaders, it has helped me develop my skills of speaking out, being assertive, negotiating ideas.

Liam’s school is only 3 minutes away by car. If we had pursued the special school it would have been a 45 minutes car or bus ride. Liam attending the local school means he knows the neighbours’ children and they know him.

Liam loves his primary school; he comes out happy and laughing most days. But he cannot tell me if something bad happened, someone bullied him during the day. I don’t worry much, I am confident that if something happened that day, I will hear about it from the other children in the school yard. They are little mouthpieces and I count on them, and the other parents, who will tell me if something happened that I need to be concerned about.

This is because the school community is a place where we belong, and the other families and children know we belong. At school events I hear parents tell me, what their children say about Liam, what funny things he did during school. They also know he is more vulnerable, and they look out for him.

Liam attending the local school – it's made a huge difference to our life as a family. If he is unwell or upset, I can easily pick him up. Liam is well known in the community; he plays with the neighbourhood children and is invited to school parties. Liam also does horse riding and swimming with his school mates; he has opportunity to play with them after school. In terms of his disability, communication and speech, therapists will say he is really doing really well, above what they'd expect.

I know that Liam is growing up with a sense of where he is from, where he and his family belong and are known. Our family life and who we are as a family with a child with a disability would be very different, if we had not made that choice for Liam to attend his mainstream local public school.

Lucia – Living a life according to my needs

Lucia's story of living a self-directed life based on her terms is told by Melanie, Lucia's sister

When Lucia, my sister, and I were growing up there was an unspoken “accepted way” how things were done for people with intellectual disabilities. Usually, it meant a closed institution where the person had no choice, no control about their daily life. Lucia is non-verbal and communicates in other ways. People who don't know her well, may not understand what she needs. When my parents got older Lucia tried to live in group accommodation for a short time, but it didn't go well, she had many restrictive practices put in place.

Meeting [name NACBO organisation] opened up a whole new way of thinking. It led me read and seek out information about the alternatives to the segregated model, which had not worked for Lucia. Staying with my aging parents wasn't an option either, they were getting older, and we needed a succession plan.

Hearing and seeing of other models especially from overseas in Canada or the US, hearing from renowned international speakers, really helped me to think differently about my sister's disability and what life she was entitled. NACBO opened up a new world, they painted a positive picture of disability. The first couple of years I took up lots of learning opportunities to get the knowledge how to help my sisters achieve her best life. It's been amazing to find people who are on the same page with you. That someone has high expectations for people with disability. Even in my own family, people have low expectations.

I didn't just come out of *one* training and thought that's it, we are doing it differently now. It took several years to make “the switch”, also to have the courage and support in place to act on the vision. Once the NDIS came, I knew that we could put our ideas of inclusion into practice. NACBO helped me get the skills and know-how to self manage Lucia's supports, how to select, recruit and coordinate paid support. But also, creating intentional connections for Lucia to engage with her community, knowing or meeting her neighbours.

A lot of people with intellectual disabilities they can't always clearly communicate what their needs and interests, so it was on us, Lucia's family and friends to learn to understand and identify non-verbal behaviour cues. Learning about these has been tremendously helpful to our family and supporting my sister. Imparting that knowledge to Lucia's support so she receives the best quality of support that is based on her needs, interests, and the way she likes things to be done. It means that Lucia doesn't have restrictive practices in her behaviour support plan. The support team are familiar and known, they understand to read and respond to Lucia's cues.

As a family we have gained a lot from being connected to [name] NACBO organisation. You feel less alone being connected to others who have high expectations of people with disability.

Lucia lives as in her own home. She is happy and well connected in her community, her communication skills have massively improved. She meets friends and connects with local businesses.

As a flow on effect of this individualised and Lucia centred model of support, the family is less stressed. I can go away without being worried, constantly checking and calling in. Because we have a great support team. And our story and sharing our experience through videos, at conferences and workshops helps to inspire other families out there, or in our local community, who meet and get to know Lucia.

[NACBO] have been immense helpful all these years, they have always helped us overcome hurdles, by talking through the challenges, provided useful resources, linked us with partner organisations and to peers, other families in our community.

Mandari – Strategising inclusive education

Mandari's story of inclusive education is told by Reena, Mandari's mother

I always knew our daughter Mandari belonged to a typical school, but it was not what professionals were telling me was possible. We had a lot of professionals involved early in my daughter's life; we went along with their recommendations. Most advice focused on her deficits, leading to Mandari starting primary school in a segregated, special unit.

A couple of years later, in 2015, I attended my first of many workshops with [NACBO], it was about *Envisioning a full life for your child*. After I felt so inspired! I realised that a different pathway was possible! I didn't know Mandari had the *right* to be in inclusive education. I also learned Mandari did not have to be 'ready' to attend school, rather that the school needed to adapt to her needs and provide the support she required.

That day changed the direction we took as a family. The following years, I wanted to learn everything about authentic inclusion. I engaged with different types of NACBO offerings: I was a regular at parent peer groups, workshops on education, living a full life, making the most of NDIS funding; I also read resources and listened to recordings on their website. What kept me interested were the stories by presenters who had similar experiences to our family, where family members with disability were living a full and rich life, achieving their potential.

Before going to the NACBO workshop, we held low expectations framed around Mandari's diagnosis of autism. Gradually, as a family, we started seeing all the things that Mandari *could* be part of, and could contribute, our focus shifted to Mandari achieving ordinary things in life – all which *is possible* with the right support.

Mandari going to a mainstream school was not straightforward. We could not have achieved typical inclusion for my daughter and our family without the continuous input, guidance, encouragement, feedback and many conversations with NACBO staff and peer groups.

Early on we created a Vision for Mandari and wrote it down, [NACBO staff] helped us refine this vision, this was important because it kept us 'on track'. When our plan to access mainstream primary school failed at first (Mandari was rejected in a couple of schools), we looked at things that we could control. We discovered a local dance studio and were accepted in their community. To this day Mandari, dances weekly and performs at the yearly public show.

A year later we finally found a private school where the principal and primary teachers were open to inclusion. NACBO staff helped me prepare for the meeting,

formulate my arguments clearly (why we wanted it, what support Mandari would require) – it was like a Gameplan!

Going into the meeting I felt confident and reassured; I knew what I was asking the principal and school was reasonable and Mandari was entitled to it. We were lucky that the school we had chosen together with input from NACBO was genuine about inclusion, they were willing to make it work.

Over the course of Mandari's mainstream education we regularly faced challenges and setbacks, for example a favourite teacher leaving. Having regular conversations with NACBO staff, who know our family and vision we hold for Mandari, was an invaluable asset! They had an open ear, encouraged us, also made sure we had realistic expectations of what the school could offer. For example, when Mandari started high school, it was unlikely we could speak to every teacher to help them understand Mandari's strengths, learning style, and our expectations. [NACBO staff] recommended centralising our communication on one teacher who could share information with the respective teachers, but also take on our concerns and questions. That strategy really worked well for us!

NACBO have also connected me to new opportunities to grow as a parent and leader!

They approached me to take part in capacity development on public speaking and leading peer groups – which I did. A couple of years ago I started working for NACBO. I facilitate the Inclusive Education Peer Group for other parents starting out of their journey, which enables me to bring in our direct experiences of and navigating inclusive education with Mandari's into the group.

The leadership skills I have learnt help me in my conversations with Mandari's teachers to create positive, constructive and effective forms of communication. I pay attention and reinforce all the positive things, what is going well in Mandari's schooling. Regularly I write letters to the teachers praising them for their efforts, sometime I include a short story about the things Mandari is achieving outside of school. Working this way means, that when difficult conversations arise, and they do, we have a foundation build on mutual respect and trust with the school staff and they are more open to 'go the extra mile', make amendments and provide additional support.

As a result of our 8 year journey with NACBO, Mandari (who is 15 years), attended several years of mainstream primary and secondary high school education. She loves going to the same high school like her brother and friends from primary school. She feels included and accepted in her class. She uses few spoken words, but her teachers keep finding roles to help her grow. For example, recently she spoke the

Welcome to Country at morning assembly. I realised how much she enjoyed speaking with a microphone. Now we are thinking of other opportunities for Mandari to present and speak in front of audiences. We see and cherish the many parts of Mandari, we are not fixated on her disability, but aim to create new opportunities for her, where she can contribute and is valued for who she is.

Connecting to and becoming part of NACBO and the community of parents, means we feel understood, we feel we belong, we are valued and supported in our choices by like-minded people.

Looking into the future, we are thinking about Mandari's post school life and her work roles. I take part in NACBOs Customised Employment Peer Group as a parent. There I learn about the principles of Customised Discovery, how to uncover a person's intrinsic motivations for enjoyment in a particular activity, and use these insights to help customise employment. Observing Mandari doing a favourite activity like rolling and mixing sweets into a bliss ball, I learnt what exactly she enjoys and how she takes control of the situation, like taking short break in between tasks. We used these learnings to create a microbusiness that builds on Mandari's love for mixing ingredients, shaping them manually, but without having to use an oven and where she has control over the process.

Marika – Peer groups empowering self-advocacy inside a group home

Marika’s story of change is told by a project worker

We established a number of peer support groups for people with intellectual disability inside group homes. Inside many older, well-established and larger services and organisations (closed systems) there are no feedback mechanisms for people to have a say and voice in the things that matter to them.

About 12 months ago, Marika, a new member to the group, attended the Consumer Peer Support group. She was hesitant at first, and nervous about speaking up in a group and speaking her mind.

From the first meeting, Marika demonstrated she had the skills to become a valued member of the group. Since attending regularly Marika has become vocal about speaking up about the things she thinks are not right. She also brings up new ideas on how management can fix the things that need changing or how to make it a better place to live.

Marika is passionate about advocating for others who may not be able to speak up for themselves, or who don’t know about the peer support group. Marika says she loves being part of the group and she feels part of the disability community.

“Self-Advocacy means I can also help other people who need it [where I live].”

”We want the same things as other people in a different way. We need information given to us in a way we can understand, and we need to help each other. Being in the group means we can help each other.”

“The Government need to listen to us or we are going to be in big trouble. They need to listen to people with disability to understand how we are feeling... People need a fair go ... We need to be strong and speak up.”

Mateo - People at the centre of decisions

Mateo's story of moving into his own home was told by Mateo (video about his experience) and his mother Jenny.

Our family has been involved with [name NACBO organisation] for close to 14 years. Over the years, I attended many (10) workshops on different topics, 2 conferences and had follow up conversations with the staff. I have been part of and led peer network groups for parents and supporters.

For us it was clear that we wanted Mateo to move out of home one day, like any young person, it is an important milestone, to become more independent, make daily decisions, live one's own life.

Since his mid-20s I kept checking in with Mateo if he wanted or was thinking about moving out. He kept on saying, "No, I want to stay here [in the family home]". I didn't know how to resolve this, I knew it was in his interest to move, because his family will not be around forever, he seemed to resist the idea.

I spoke to his mentor and they suggested we run a Visioning session around Home for the family. We worked through a lot of the details, had a list of questions to work through. Like where would the ideal home be located, how many people will live there, what type of furniture will it have, ... it was about spelling out all the details, really making the idea come more alive for Mateo. We asked him, how many rooms would he have, what sort of furniture and will you have a pet?

I realised Mateo could imagine his future better, he had a real vision afterwards, he started telling everyone he would move out in 6 months, although we had not even found a property. Mateo even started looking on the internet for houses to rent.

We ended up buying a small flat close by, we were lucky enough we were able to do it, having a long tenancy was really important for me. Over the next months we worked out all the details, how would his support work, getting to work, medication, socialising and so on. It ended up to be easier than we thought. Because Mateo's home is in our neighbourhood, a place he already knew well. Within a week he knew the main walking routes by heart.

The long term plan is to have an ILO application with the NDIS. [NACBO organisation] are guiding us with that, because the process is very new. In the meantime, it worked out that Mateo's older brother wanted to move, and the two brothers decided to move in temporarily together. It was a really easy transition while we are in the application process for the housemate support.

Moving out of home at 28 years was a big step for Mateo. He grew immensely in his skills. He had to learn how to use the new appliances, washing machine, how to get around the neighbourhood, many little things of everyday life.

I am certain Mateo loves where he lives now. He hardly ever comes home! Even though it is a 5 minute walk. I started a weekly family dinner to have all the kids together once a night, because everyone was happily doing their own thing. Mateo is a very proud home owner, he welcomes you with a broad smile. He is problem

solving. I used to make his lunch for his theater group, he said “mom I don’t need it, I will just go and get sushi along the way!”. It’s these everyday decisions and choices he gets to make, and he loves it.

Mateo - Incremental capacity-building

Mateo’s story of becoming fully independent at work is told by his mother Jenny

Leaving school Mateo kept telling me he didn’t want to work at the factories (sheltered disability employment). His school had organised a work experience there, he didn’t like it. I was aware of a customised employment service I met at a Conference organised by a [NACBO organisation]. For a few months we paid them to work with us to develop and customise work for Mateo.

His first work was in a busy mall, at the small fruit and vegetable grocer. He learnt how to catch public transport to attend there. He also had an office admin job two mornings a week. However, this work stopped with Covid and the lockdown. Today, Mateo is looking for new employment. The NACBO organisation is helping us to form relationships through a network approach to employment. , and via his Circle of Support

Mateo still works once a week at the grocer. His role and work there was set up with the support of the customization, or “job carving”. The service found and matched the skills and interests Mateo had or could develop, and what the company needed. They were there every step of the journey to guide Mateo and the business. Today, Mateo performs all the tasks and roles himself and safely, stacking boxes, crushing card board in a machine, organising the items for sale. He doesn’t need any support or prompting.

However, when Mateo was starting out, the service we hired to go through the customization with us, they were heavily involved at the start, and gradually shifted more responsibilities to Mateo.

Mateo is proud of his work and enjoys the company of the other workers. He loves putting on his work uniform, especially his work cap. He is also very keen to find more work, to learn new skills, and it takes time to find employers that are open to “job carving” making amendments to afford people with disability opportunities.

Melissa – How I participate in my local community

Melissa told her story of her social and business connections.

I used to attend a day service, three times a week for 3 years. That's close to 20 years back. It was okay but I didn't like it very much. I had to do what everyone else did, I didn't get much of a say about what I liked or enjoyed doing. Most of the other people in the group were older than me.

My mother got in contact with [NACBO organisation] in 2004 and went to some workshops. Later one of the [NACBO organisation's] staff came and spoke to me about my dreams. I said I wanted to go on a guided tour of the Sydney Opera House and move out of home also to get a job, like my brothers.

My mother started working with NACBO, attend their meetings and groups, while we were making changes in my life. I joined the local gym and a choir. I started a job at a Mexican restaurant for a few years. Recently I joined the Football Club's banner making group with the Cheer Squad.

About five years later, it took a lot of planning and organising, I moved into my own apartment! I live there with a flat mate without a disability. I have since moved several times, now I live in my own flat. I love having my own space and freedom. This has helped my independence a lot, I am learning how to do things like cooking and cleaning, and shopping.

In 2016, my Circle of Support helped me to start my own business. I make cards and canvases. I paint them, then I get them scanned and printed. I then sell them to friends, family and other local businesses.

I have been invited by my local NACBO organisation to present and speak about these things at conferences and workshops. I have made 3 videos about my home and my business. My local NACBO organisation help me to facilitate my Circle of Support, I pay them with my NDIS funds. They make sure that we do what I want to happen and help me plan for my future.

Monique – Follow up guidance through peers to act on a vision

Monique's story was told by her mother Tammy.

As a parent of a young daughter with an intellectual disability, we only had one thought for her future, she would go to an ATSS during the day and eventually live in a CRU. All segregated settings! Our daughter had attended Specials Schools so we assumed that this would be a natural progression. The only reason we thought this was because we were unaware of any other options.

Once our daughter left school, she attended an ATSS for 3 years but refused to go after that time. She also refused to consider trialling a CRU to live in. We needed to find another way!

I heard about a Capacity-building event being run by Belonging Matters with a well-known speaker. I was very naïve about what I was going to hear but I attended this, and I came out a little more hopeful than when I went in. I attended as many events as I could.

Due to the exposure of many capacity-building events held by Belonging Matters, with many professional speakers, as well as hearing firsthand from parents who spoke about their journey, my eyes were opened to many other options. The topics covered at these events varied between people with an intellectual disability living in their own home, work, recreation and running a small business. I also heard about the value of having support workers that also believed in our vision and worked separately from an agency.

In saying this, the confidence to take this knowledge and act on it did not happen by attending one event, but many events. As a parent you need to be convinced that this would be possible for **your** daughter and more importantly **how do you start** and **how to you make it happen**. You also need to know that if you take this journey to change things you will get support along the way. For me this was the knowledge that I could get support from Belonging Matters.

After a lot of discussions, our family were given a lot of assistance to apply for a Housing Grant from the Government. This application was successful, and a small number of families formed a family governed initiative called Living Distinctive Lives.

Living Distinctive Lives (LDL) consisted of a group of families all with the same vision. For each of our disabled son/daughter to live in their **own** home with or without a housemate. This housing was to be within their individual communities, not living together.

We met every month and a representative from Belonging Matters attended each of our meetings for several years to encourage us to stay on track and hold onto our vision, despite all the hurdles along the way. After many years, we all achieved our visions and each son/daughter had realised their dream to live in their own home.

During this journey, each of the parents gained a lot of knowledge and confidence in what we were doing. Each of us have consequently spoken of our experiences at various events run by Belonging Matters. We hope we have helped other families to understand first-hand the importance of the vision and what can be achieved. We have also encouraged other families to explore having a similar group as LDL as it helped all of us to keep on track. We also have encouraged the families to reach out to Belonging Matters for support and assistance when they are feeling overwhelmed. The value of either talking to one of their representatives or attending one of their events is very inspiring and helps you to maintain your vision.

Our daughter has also been asked to present at a few of the Belonging Matters' events. She tells her story and empowers other young people with a disability as to what is possible. One young woman saw our daughter talking about home and relayed to her mother that she wanted to do the same. The mother told me later that they have also achieved their goal of her living in her own home. It is very powerful to hear directly from the person who has experienced similar hurdles in life. This networking of families by Belonging Matters is vital to others gaining similar knowledge.

The organisation also runs events that are extremely useful for our daughter's support workers to attend. We do this as often as possible because we have found that the quality of the support team is enhanced enormously. Our support team understands the vision we hold and why. They learn from these events the best way to support our daughter.

To safeguard the inclusive lifestyle and long-term vision for our daughter, we were advised and again assisted by the organisation to start up a Circle of Support for her. Over the years this has changed in many ways but continues to be a valuable support for her. Besides the volunteers who attend the Circle meetings 6 times per year, we employ a facilitator to run the meetings. We learnt very quickly that it is very easy for the meetings to get way off the track, or the meeting runs for too long and achieves very little. You then run the risk of losing members. With the facilitator we get the best out of the meeting.

The organisation ran a webinar titled 'Safeguarding the Future.' During this event Another we were made aware of other important safeguards. One was the importance of putting onto paper everything that is in both my husbands' and my head relating to the day to day running of our daughter's life. This is extremely

important for safeguarding her future. This information forms a document covering the whole of her life so encompasses her vision, home, business, medical, support teams, financial, NDIS funding etc.

One of the best outcomes of this has been that our daughter has requested that a small amount of time every Circle meeting be allocated to this topic. She is asking questions like “who will help me with ... when mum and dad are not around”. The more she asks these questions, the more prepared she will be, and she is realising that she will have support around her when the need arises.

In summary, without the opportunity to hear, learn and be guided to follow the vision that our daughter and we now hold for her, she would still be living at home with her aged parents. She would not have experienced independence, or how to look after some of her affairs. She would not have a small business of her own, would not have a high-quality support team, nor have a Circle of Support. But, most of all she would not be happy.

Nina – Exploring pathways to open employment

Nina’s story of creating diverse open employment told by Simone, her mother

Nina is in year 11 in a mainstream high school. She has many talents and skills, she learns well in the right environment, when accommodations are made for her learning disability. During school she attended congregated work experience with other students with disability, it was very much a token experience. We didn’t get other support from the school to do anything else.

I wanted to explore other options for Nina’s career and work pathways but didn’t know where to start! All I remember was worrying about what would happen once school ended, losing the structure, social connections that come with school! Her teacher introduced us to NACBO, I was curious and attended a seminar about School to Work. This started me on our way, thinking about what is possible for Nina’s future, importantly the things we need to put in place *now*, while she is still at school, and preparing for post-school.

Since the first workshop in 2021, I attended many more events and seminars! At least 8-9 different workshops on topics: Building a Context for relationships; Towards a Better Life; My Home my Way; Discovering Work – Getting started for Year 9 and 10; Work Experience; Getting Your Job off to a Good Start; Imagining Home and Moving from Vision to Reality; and Supported decision making! I am also an eager participant in two facilitated peer groups for parents, one on open Employment and the other on Customised Employment. I really connect well with their ideas and how NACBO impart their knowledge families learning through others, like the facilitated peer groups, learning with other parents in specialised workshops and getting inspirations from storytelling – I loved their Conference – Get that Good Life. I watched it over and over, you get something else out of it each time!

As a family we have opened up many opportunities for Nina to grow, learn and have experience, like horse riding, pets, swimming, crafting. We didn’t pay much attention to how they could translate into future work. One of the main messages I have taken from the employment related workshops and peer groups is about asking and understanding ‘the Why’ – why does Nina enjoy a particular aspect of a task, what motivates her, excites her, why does she keep coming back to a particular interest. We knew Nina loved dogs. We have one at home. But after these workshops I started paying critical, almost inquisitive attention to what it was about her relationship with the dog. The idea behind discovering your family members’ intrinsic interests comes from a customised employment lens. It really allowed us to think more broadly, outside side our own preconceived ideas about Nina’s interests and how to support her.

My husband and I started making long lists about all the things Nina liked and why. NACBO supported us in this discovery process, we had meetings with them to discuss what we were finding, but also listening to other people's stories, what to do once you have found an interest and how to develop the skills for it to become valuable work, employment. Attending the workshops and meeting other parents gave us the confidence to try out work experience in open employment.

Through a connection of mine, Nina did a work placement in an office environment. We made sure it was set up in a way that works best for Nina. Through NACBO I have the confidence to speak up for Nina and demand the things she needs for a positive experience. For example, I requested Nina could spread out the work experience, so it was half a day a week over a longer period, rather than a blocked. Understanding how she learns and build skills successively informed our demand for this condition. She started last year, and she is still doing that this year. What is great about this work experience is she is trying out different roles and tasks under the supervision of people who understand and know her by now. Nina feels very comfortable and part of the team. It has given her the confidence to try out other things outside of work.

We are part of a small group of parents who meet with an experienced mentor to talk about Customised Employment. We are also exploring a microenterprise build on sewing and creativity, one of Nina's passions she picked up at school. With NDIS funds we hired a sewing teacher who works with Nina to grow her skills and confidence. Nina now creates her own personalised crafts and Christmas decorations. It is something she does herself and she enjoys it. We asked a family friend to help set up a website, to market Nina's crafts, and is Nina learning skills to take and upload photos of her creations to her website.

Being involved with NACBO has opened up new opportunities and avenues for Nina, socially and employment wise. She is learning to connect her passions to skills and being more independent.

As a family, it has given us a whole lot of hope for the future. The confidence and the tools, resources to support Nina to develop and find meaningful paid roles. We learn through connecting to other families, our peers with similar experiences, also through the input and personalised conversations we have with NACBO staff. Finding [NACBO] has been life-changing for our family!

Peter – The importance of friends and allies

Peter told his story about how he was able to move to his own home with the support from his allies who had guidance from their involvement with one NACBO organisation

Hi, I am Peter. I don't have any family members in my life. I have lived in a group home for close to 30 years after my foster parent got sick when I was a teenager.

Where I live, the workers are nice, I live with five other people with disabilities I didn't choose. Sometimes I get angry at my housemates, when they are too noisy or loud, it's not their fault, it is not where I want to be and live.

I am 46 years old and have not had a chance to do what I want. I want to build my life in the community, supported by my support workers. Since the NDIA planner asked me seven years ago, if I would like to move, I have told my good friend Sabine, from work, and my other friends, I want to move and get a house of my own!

Some days, I would ask them four times a day if they had any news for me. Recently my friend Sabine found a NACBO organisation to help us plan how I can move out of the group home.

I know it would be impossible for me to move out if I didn't have my friends. People say that the NDIS system is complicated. Sabine and the NACBO organisation think we should start a group called a Circle of Support to help me plan this move and reaching my goals. The NDIS funds a facilitator to lead a discussion with me and my friends.

About a year ago, my friend Sabine helped me rent a little two-bedroom house in my local area. This change has been really good! I am brushing up on my skills that I just didn't use or couldn't learn at the group home. On Tuesdays, after work, I go to my home. There I plan my meal and cook it with support. My friend, Sabine, says we need to make sure I'm safe in my home to begin with, and then the NDIA can save money.

Unfortunately, I have to go to a special court to fight for my NDIS funding, so that I get the support to spend more than one day at my own place. The NDIA wants me to live in a house with two other people with disability. I don't understand why. I prefer to keep my house, the unit I am renting, and slowly want to spend more time there. Post script: Peter is living in his own home during the week and returns to the group home on the weekends

Ramona and Bogdan – The power of peers to shift family expectations

The story is told by the program manager of a 6 week workshop series delivered over a 3 month period

Bogdan is an 83 year-old grandfather and sole carer for his granddaughter Ramona. Ramona lives with an intellectual disability and Autism and receives NDIS funding. Bogdan found out about the Skills capacity-building workshop series and attended.

At the first workshop he spoke in depth with our team. He said he was the nominee for Ramona's NDIS plan but often struggled to make sense of the information he needed to provide, or that was provided to him. Bogdan also admitted he was not overly confident interacting with Ramona's Support Coordinator, accessing online tools or information, or registering for online information sessions.

The sharing of information, stories, values and support from staff and peers throughout the 3-month workshop series assisted Bogdan – who prior felt isolated due to his age, limited digital literacy also language and cultural barriers – to connect with other family members. Connecting with others people and their experiences was a powerful motivator for Bogdan to reflect on his role.

By the end of the 3 month workshop series, Bogdan reported he had gained important and valuable skills in understanding how he could support his granddaughter in different ways, including with her NDIS plan, and had gained a deeper understanding of how the NDIS works.

Importantly, Bogdan reported that through the stories and discussions with other attendees (parents, grandparents, extended family members) over the course, he had altered his attitudes and expectations towards people with disability. He now understood and accepted that supporting people to make their own choices was far more acceptable and beneficial than doing things 'to' people and 'for' people.

Bogdan said that “this shift has led to changes in my role and relationship with my granddaughter”. And it was already benefitting them both. He reported that this has given him “a deeper consideration for my granddaughter's future, focussing on her achieving her own goals rather than purely what I perceive as her support needs”.

Improving his NDIS knowledge and information also assisted the family in advocating for changes to Ramona's NDIS Plan Review.

Ultimately, Bogdan reported he realised that it is more important for Ramona to socialise and develop skills “to have more social and community connections” and

“emotional support” not just to “be looked after and receive functional everyday support”.

Ramona was accessing more therapy hours and looking to get her Drivers Licence to be more independent in a regional area. Bogdan’s greater awareness, higher and changed expectations, combined with supporting Ramona’s choices and independence, will in the longer-term lead to improved community outcomes and connections for Ramona.

Randy – Building leadership by people with disability

This story is told by Randy a young man with disability. The story was developed as a presentation for an advocacy conference.

First, I want to thank [my mentor] for the opportunity to speak to you all today. Through NACBO I get to learn from the expert in the field that I am passionate about autism advocacy.

NACBO organised [name of staff], the President of Physical Disabilities Australia to talk to us about advocacy. Through him I gained a much better understanding of the role of an advocate. The different types of advocacy involved, and how to be a good advocate, so on and so forth. His honest sharing gives me a valuable insight into the career I want to be in.

Through [name of mentor] I also learn that to be a true advocate, I have to advocate for others as well, not just for myself. In the early days of my advocacy journey, I only wanted my story to be heard. I also learn about the language of advocacy. I learn the importance of being sensitive to other people's feelings in delivering my speeches. How I can show more consideration for others, be more cautious with my words. I learn the power of humility.

The opportunity to be guided by such an excellent mentor is more than I could ask for. Today, I feel more confident in navigating my post school life, and my advocacy microenterprise.

[name mentor] has inspired me to do TED talks in the future. It is my passion and desire to present internationally and use my platform to make positive changes.

Sammy – Peer mentors, leaders in their own right

Sammy's told her story of what it means to be disability advocate and leader.

Sammy is a Peer Facilitator of a youth self-advocacy group and sits on the Board of [NACBO organisation]. Sammy joined the Board her early 20's with a strong passion for disability advocacy, and then commenced an unpaid role as a peer facilitator.

Hi, my name is Sammy, and I am a volunteer facilitator for the Youth self-advocacy group. The peer group consists of 5-8 young people with disability who meet monthly at different locations.

Being part of [NACBO organisation] is an amazing adventure for me. This opportunity has helped me increase my confidence in speaking to people I don't know very well, presenting to groups, and helping to coordinate groups. Because I feel more confident, I am also thinking about approaching new employment and soon will be co-chairing a Facilitator training night.

I have also gained experience with working in a team situations and problem solving issues when they arise at our meetings. I am learning everyday about myself, my strengths and I want to share what I have learned with others.

Sammy reflects how her confidence has grown through the experience of being in a leadership role, over time. "I've matured a lot over the past year or so... on the board, I've learned to stand up for myself."

Part of Sammy's role is to chair the meetings, to manage time, and ensure everyone has input to the group. "I feel proud of myself and feel I am standing up for the meeting."

An important part of becoming confident to run peer groups by herself was watching and learning from [staff at NACBO]. "Kristie was a great mentor, I learned so much through her and by Kristie giving me feedback and guidance how to do things differently".

Through these roles, Sammy said she learned about herself everyday, it also allowed her to share these learnings and connect with the broader community,

I feel I am on a continual journey of self-discovery... I am really proud of who I am today and how far I've come!

Being on the Board of Directors [name NACBO organisation] means that I feel connected to the community, as a peer group we are fortunate, we discuss how we can connect to the community...I think as a peer group we are going forward and growing up, with those changes, we will be able to connect to the community differently over time.

Prior to taking on different leadership roles at [NACBO] Sammy said she often felt “self-conscious” or “not good enough” comparing herself to others. Today, Sammy feels she has developed confidence to share appropriate information about herself, use and communicate strategies with others (eg colouring in during meetings to support her attention and regulation).

Sammy’s goal is to take on the role of Chair by the time she is 30 years old,

“Women with autism can do these roles...I’ve always wanted to be an autistic advocate. It’s difficult being a female autistic person in this world. I want to show people I’m autistic, I may not have the same cognitive skills as others on the board, but I’m someone who wants to learn. I’m someone who likes to learn and show people I can do anything.”

Simon – Empowering families for people with disability to reach their potential

Simon's story of connecting with other people was told by his mother, Cecily

I found their website and it inspired me! After attending the first two workshops it got me thinking how to approach things differently. First, I felt a bit overwhelmed, in some respect, I thought of myself as a failure, because my son went to a special school. But I continued with [NACBO] because the door had opened, they were accepting and welcoming.

Working with NACBO slowly changed our thinking about disability. Before, disability in our family was talked about "as the worst thing that had happened to us". Simon uses little to no language, he has an intellectual disability, and other people, including his family, made assumptions about him, we held low expectations. Since being part of NACBO it has changed how we 'do things', it has made life with Simon more like a fun adventure, a discovery of opportunities, where many more things are possible than we ever imagined!

Today, we live our life and are "Simon-centred" and not "service centred". With everything I decide for Simon, I ask myself, "would I have done this, assumed that, with my two other children?". As a family, we think of Simon as a person who does things, who brings joy to our and others lives, who has many roles and contributes to his community. We self-manage his NDIS funding to support Simon to successfully run his microbusiness and develop new relationships in the community. Over the last couple of years Simon earned thousands of dollars which we donated to charity. We are looking to upscale his business to make it sustainable in the future, for Simon can earn his own wage. That's our long term goal!

Looking back to when we started, we have fundamentally changed how we live life as a family. As a mother, I now understand it is not my job to do things for Simon, or make his decisions, but to open up doors for him, so he has different opportunities, grows and learns. It is also about listening and observing closely the things he enjoys doing and what he doesn't like. And learning how I can let go and believe in his capabilities.

A recent example is from Simon's recycling business. The van we use to collect recycling and deliver it to the sorting facility needed fixing. As Simon loves assembling Lego, he's extremely good at it, his job mentor thought it would be an opportunity for him to learn about van maintenance. We involved Simon in all aspects of the repair – from checking what was wrong, removing the part (a bolt in the door), going to the mechanic to find the part, and installing it later. This way he gradually grows his capacity to run his own business. The next time when the

door doesn't close, he will remember to check that part. He has an exceptional memory. While doing the repair, Simon also spotted several other bolts and things that needed fixing. He was seemingly proud of it.

Another example of "Simon-centredness" is how we support his communication with others (who he is, what he loves and what he has achieved). Over the month we take photos of all the activities he does, the people he meets. At the end of each month, together we assemble the photos in a newsletter. Simon picks the photos to include, says a couple of words, and I write a short sentence based on his input. The newsletter is an opportunity to reflect what we did that month, if we are working towards our Vision for Simon, and document what he achieved, the relationships he formed and maintains. The newsletter goes to a network of friends, family and people in Simon's network. It fulfills two functions, first it gives Simon a way of communicating and remaining in touch with a broader group of people. Solidifying his vision and safeguarding it, because his siblings, cousins, neighbours know who he is and what he does. Second, it creates a dedicated time for us to stop and take stock of what happened that month. See how it aligns with the Vision we have for Simon and his life.

We have a second document that Simon takes to meetings to introduce himself, tell other people and professionals who he is, what he likes, what his passions are. Simon has ownership of the document; we update it together.

These are some examples of how NACBO has helped us to change our ideas about disability, have a positive vision for Simon and his life ahead, how we can support him to be independent and grow, build relationships, but also plan and safeguards his future.

Simon and Cecily - Investing in family leadership

Cecily, Simon's mother speaks about her experience of being a leader

I connected with NACBO organisation in 2020. It took a couple of months, where I explored their website and read the newsletter, before signing up to an all day conference. The conference was on Finding Open Employment! It was a life changing experience! I could not believe the stories of people with different types of disabilities, and the creative ways how people and families had achieved amazing things in life.

Since that first workshop, I attended 10 more, on different aspects how people with disability can live an authentic life, - friendships, home, employment, supported decision making, and having roles in the community. All focused on how we, as a family, can empower Simon to achieve the good things in life, be valued and have different roles.

Successively, I took part in different peer groups, which were all on the themes – of relationships, work, imagining home and living in the community. These groups have been pivotal to learn and hear in-depth from the experience of other parents, families. The groups allowed me to share our own achievements, also speak about the setbacks. Find ideas, inspiration to the challenges we were facing at the time, get the encouragement from peers.

More recently, NACBO have supported and encouraged me to become a family mentor, and share Simon's experiences in one of their workshop series, Make the Most of your Funding. I get to speak about what we have learned about setting high expectations and changing the language we use at home around disability; how we created Simon's microenterprise, and a big focus is on developing relationships with his siblings and cousins and new people in the community. We use ideas based on the tools and stories from NACBO (like monthly newsletters, using flash cards to help him remember and learn the names of his business partners) to support Simon, who uses minimal spoken words, to be known and valued by others.

Being able to give back to other families and peers through sharing our journey makes me realise how far we have come, how much has changed in our family life, how we think of, see and we value Simon.

Susan – Parent leader

Parent and leader in capacity-building and peer networks shared her experience of becoming a leader

Exposure to the right sort of capacity-building does a number of things. What becomes obvious is that there are many and varied ways of doing things. However, often what is presented is something that suits the needs or agenda of the provider of service. They are conflicted although don't always realise it. What they offer isn't necessarily what works or is best for an individual.

Values and vision are key to good capacity-building but are often ignored. Experts and services come and go but friends and families, particularly families, are much more likely to be in there for the long haul. They are also much more likely to know what is needed – the passions and desires of an individual so investment in this group is critical. Skilling up families to understand the system, building their confidence to know what to do, ask for and know when it is delivered is also key.

The “gentle touch” of the disability service system is inadequate and sometimes dangerous but can be packaged in a beguilingly seductive way. We need to beware when supporting our families of this.

How NACBO helped me to build my skills, leadership and capacity

Being around disability teaches you many things including:

- Experts don't often listen to parents or people with disability. They think they know best, and they often don't read or believe the research. Particularly if it contradicts their service model.
- Many false promises will be made along the way.
- Don't waste your time with negative people. There is no shortage of negativity.
- Learn how to negotiate.
- You need to be forever vigilant. People in power, or powerful organisations, rarely take risks or take seriously something new. They can sometimes reverse what you thought was settled and even seek revenge if you are too troublesome.

When a person with a disability or their family sets out to find an ordinary life for themselves or their family member, they know very little of this. Personal experience can be a good teacher but that is greatly enhanced by a better understanding of how things are and what can work with striving for typical experiences for our family members. I have found capacity-building that includes workshops, training, being pointed in the direction of good research, hearing the experiences of others and sharing your own experiences to be invaluable. We have learnt a lot. Capacity-building makes it possible.

My son's life has been changed.

Barriers to building capacity and skills

If you have someone with a disability in your family and you want them to have a good life you will be busy. And you will be busy for a long time. You get tired. Often there is insufficient time and energy. It is all too easy to surrender to the disability support system when this happens.

Despite all the extra resources put into the disability support system it remains much the same. The NDIS has been captured by the traditional disability support system and has resulted in the system providing much the same only bigger. It hasn't been transformative.

It remains difficult to access good information. Traditional disability service providers and many institutions in society often act as gate keepers for the dissemination of information. They will only distribute information that suits their needs which mostly is about the provision of segregated services such as day programs, group homes etc. Anything that emphasises accessing mainstream services etc is shunned or hidden. They are major controller of information flows. This needs to change.

Opportunities for the future of capacity-building

There needs to be a much more concerted effort to have mainstream services and institutions to cater in a genuine way for people with disabilities. At the moment much of capacity-building is focused on equipping people with disabilities and their families with the skills and capacity to confront a system that is largely unsympathetic to their situation. This is essential and should continue.

However, much more effort is needed to encourage mainstream services and institutions of our society to willingly and creatively include people with disabilities in their everyday activities. This would make it easier for already tired and time poor people with disabilities and their supporters to access the mainstream world. At the moment people with disabilities and their supporters are being asked to change the world largely on their own. The world needs to be made more willing. I recognise that capacity-building can't do this on its own either, it mostly introduces the possibility, but more effort at making the world receptive would help.

Tej - Follow up to build confidence to self-manage funding and supports

Tej's mother Lamia told his story about follow up support

My son Tej has high levels of support requiring 24/7 support using assistive technology. He lives at home with me. I was hoping the NDIS would give Tej a better life. We received very little support, and we had no choice about services. When the NDIS came families had a lot of questions. So, I attended one of the NACBO workshops about the NDIS and how to self-manage funding.

After attending the first workshop I thought, I could never do that, manage my son's funding and plan. However, they kept sending me emails. I attended more webinars and things. Later, I joined a peer group for self-management, some people in there were very savvy with numbers. It was intimidating for me; I was in my mid 50s and had no background in business or accounting. But I learnt that other people in the group were doing it, they had been new too, like myself. The other group members gave me lots of tools, ideas and confidence to try it out myself, how to do plan management in practice. I started experimenting a bit.

Tej still lives at home and we self-directed his funding, we hire his support workers. It gives him more freedom to make choices, who we employ, which services he needs. Also, we look around and find the best price for something.

Today, I am still involved with a peer support group, this group is about keeping everyone up to date with new information. Other people in the group are very savvy, there is one young man with disability in our group who always reads the NDIS updates. The group come up with new ideas for assistive technology, budgeting tools and information, changes to the NDIS portal, or which services are good. It's a resource I can rely on to keep up to date with the regulatory changes.

Tom – Moving into a home to call my own

Tom’s story is told by his mother Ruby and a NACBO mentor

Tom lived with his parents and siblings in their family home until 2005. At 23 years he had a short stay in a disability residential care facility, where his levels of anxiety were heightened to the extent that his family removed him for fear of his safety. Tom returned back to the family home. His family were unsure what his future would look like. They were looking for other ideas.

A few years later Tom’s mother Ramona was sparked by stories she heard from one of the NACBO organisations], about a woman with complex disabilities who had moved into her own home; Ramona thought to herself, “If she can do it then why can’t Tom?”

Ramona spoke to the local coordinator of a small family governed collective (assisted by one of the NACBO organisations). They talked about her ideas for Tom living in his own home and agreed it would be a good idea. Together, Tom, his entire family and Circle of Support start to think about Tom moving into his own place. Tom was 34 years of age.

One of Tom’s first expressions of joy, as he moved into his first own home was to twirl his arms outstretched with a huge grin on his face... as if to say – “There is so much space – and it is all mine”!

Moving into his own home, with a range of supports, including housemates without a disability , brought many new people, connections, experiences and social roles into Tom’s life.

Today, Tom continues to live in his own home. Since 2014, he has taken up several paid jobs from delivering scripts for a pharmacy, to delivering pamphlets for a local real estate agent. Some of these paid work roles lasted for over 6 years.

Tom’s Circle of Support supports him to pursue his passions for photography and painting. With their support he has set up a small card sales business based in local coffee shops he regularly frequents.

Currently, Tom is following a new interest in bee keeping, which he does in his small garden. He loves “smoking” the bees and he is also a student of a bee keeping class. Over the years, Tom, his family and allies have worked with and received guidance, ideas and resources from a NACBO organisation to help them to create new opportunities and connections for Tom.

Wandga - Building capacity in isolated communities

The story of change is told by the facilitator of the workshop series

There is a very low level of awareness about disability rights and a lack of understanding about navigating the NDIS system in the Bhutanese community. Without this capacity-building series of workshops, it's possible that this community member, Wandga a young father, would not have known that he can initiate a review of his daughter's NDIS plan. He was not aware that it was possible to design a plan that included services and supports that were more suitable and also culturally appropriate.

We made sure that the workshop series was culturally appropriate and first held a co-design workshop to understand exactly how to achieve this. Co-designing the Disability Awareness and the NDIS workshops with Bhutanese Community members living with disability ensured the workshop content was culturally appropriate, highly relevant, and accessible to attendees, people with disability and their supporters and families.

For example, we invited guest speakers from targeted government agencies and community organisations who could connect people with practical information about important supports. Providing attendees with information about their rights and the services and supports that are available to them increases their confidence and ability to engage with the wider community.

Wandga, one of the attendees reported, "By attending the workshops in person and with Nepali speaking interpreters, my community members and myself were able to understand what was said and we gained a lot of knowledge from inspirational and expert guest speakers about disability, Support Services, Support Coordination, Centrelink, Employment, and Advocacy."

"Before the workshops, people living with disability in my community were isolated and were not celebrated but after attending the Disability Awareness workshops last year, we were able to organise our first ever International Day of People with Disability event on in December".

After attending the Disability Awareness and NDIS workshops, Wandga reported he had gained confidence in approaching service providers for support services, he felt included in the community which has increased his confidence with being involved in community events. Increasing knowledge and opportunities allows for improved outcomes and the development of more valuable community roles for people who were previously isolated.

Appendix D. Survey findings

As part of the evaluation a survey was developed in consultation with NACBO leaders. The questions drew on a previous survey run by NACBO in 2019.

Data was collected online using Qualtrics for a 4 week period during October and November 2022. Each NACBO organisation emailed surveys to their contacts, including people with disability, family members and support workers.

In total, the six organisations sent 13,776 invitations, with an overall response rate of 3.5%. While this rate is low, those organisations which sent the largest numbers of surveys also received the largest numbers of responses. The response rate varied widely from 45.8% to 1.7%, with those organisations sending fewest invitations having the highest response rates.

Table 1: Response rate NACBO survey 2022

	Invitations (n)	Completed (n)	%
Total	13,776	482	3.5

The data was cleaned, removing responses which were largely incomplete and analysed using SPSS. Qualitative responses to open ended questions were analysed thematically using NVIVO. Identifying material in the qualitative data was removed or anonymised.

About the survey participants

The survey was completed by 482 people. These came from all the NACBO member organisations.

Table 2: Organisation survey participant used the most

	n	%
Organisation 1	113	23.4
Organisation 2	112	23.2
Organisation 4	82	17.0
Organisation 6	82	17.0
Organisation 5	70	14.5
Organisation 3	23	4.8
Total	482	100.0

Of those who completed the survey, most (63.1%) reported that they were parents or people with disability. Another third (30.5%) said they work with people with disability.

People with disability constituted one-fifth (21.6%) of participants.

Note that many participants selected took the option of selecting more than one response for this question.

Table 3: About survey participants

	n	%
I am a parent of a person with disability	304	63.1
I work with people with disability	147	30.5
I am a person with disability	104	21.6
I am a sibling or other immediate family member of a person with disability	36	7.5
I have an informal or unpaid relationship with the person I support, other than family (e.g. friend, advocate, neighbour, work colleague)	34	7.1
I am an extended family member	20	4.1

Note: Percentages can add to greater than 100 as participants could select more than one response.

Just 6 survey participants (1.2%) identified as Aboriginal or Torres Strait Islander. This contrast to 3.2% of people in the whole Australian population.

53 participants (11.0%) said that they were from a culturally or linguistically diverse background. In Australia, 51.5% of people were born overseas or have a parent who was born overseas and 24.% of people use a language other than English at home.

Table 4: Cultural background of participants

	n	%
Aboriginal or Torres Strait Islander	6	1.2
Culturally or linguistically diverse background	53	11.0

Participants lived in States and Territories across Australia, with most in Queensland (23.2%), New South Wales (19.7%) and South Australia (18.7). Although no NACBO organisations are based in Tasmania or the Northern Territory, a very small number of participants did connect with NACBO from those jurisdictions.

Table 5: State or Territory of residence

	n	%
Queensland	112	23.2
New South Wales	95	19.7
South Australia	90	18.7
Australian Capital Territory	62	12.9
Victoria	61	12.7
Western Australia	21	4.4
Tasmania	2	0.4
Northern Territory	1	0.2
Other/missing	38	7.9
Total	482	100.0

Nearly two-thirds of participants (60.4%) lived in capital cities, with another quarter in regional areas (25.1%). 7.1 per cent said they lived in rural or remote parts of Australia.

Table 6: Location

	n	%
Capital city	291	60.4
Regional or regional city	121	25.1
Rural or remote	34	7.1
Don't know/missing	36	7.5
Total	482	100.0

Contact with NACBO organisations

Half of participants (50.4%) had first had contact with a NACBO organisation within the last 4 years. Nearly a quarter (22.8%) first connected between 5 and 9 years ago, and another quarter (26.1%) 10 years or more in the past.

Table 7: When survey participants first connected with NACBO organisation

	n	%
0-4 years ago	244	50.6
5-9 years ago	110	22.8
10 or more years ago	126	26.1
Missing	2	0.4
Total	482	100.0

Participants were asked if, in addition to the main NACBO organisation that they work with, if they also connected with other NACBO organisations. Just over half (57.7%) worked with just one NACBO organisation. The remaining 46.3% worked with other NACBO organisations as well. As demonstrated in Table 8, these were distributed across all NACBO organisations.

Table 8: Participants connected with multiple NACBO organisations

	Organisation %						Total
	1	2	3	4	5	6	
Organisation 1	NA	28	17	5	34	11	14.9
Organisation 2	29	NA	13	7	36	21	17.4
Organisation 3	7	12	NA	2	16	5	7.9
Organisation 4	8	16	13	NA	14	11	10.2
Organisation 5	25	33	9	6	NA	16	17.6
Organisation 6	23	35	9	4	20	NA	17.4

Note: Percentages can add to greater than 100 as participants could select more than one response.

Use of capacity-building, follow up and leadership

Participants were asked which capacity-building support and resources they had used relating to information and learning. The most common, used by half to three-quarters of participants, were workshops (75.8%); resources such as podcasts, factsheets, videos or publications (67.9%); webinars (58.3%) and websites (54.6%).

Table 9: Capacity-building support and resources used by participants: Information and learning (n=480)

	n	%
Workshops	364	75.8
Resources (podcasts, factsheets, videos, publications)	326	67.9
Webinars	280	58.3
Websites	262	54.6
Peer networks or discussion groups	228	47.5
Conferences	223	46.5
Courses (multi day)	137	28.5
None of these/missing	11	2.3

Note: Percentages can add to greater than 100 as participants could select more than one response.

Participants were also asked which capacity-building support and resources they used relating to follow up assistance. By far the most prevalent response was one-on-one conversations, selected by half of all participants (51.9%). Smaller proportions used coaching (14.0%), circles of support facilitation (13.1%) and community projects (11.0%).

Table 10: Capacity-building support and resources used by participants: Follow up assistance (n=480)

	n	%
One on one conversation	249	51.9
Coaching	67	14.0
Circles of Support facilitation	63	13.1
Community project	53	11.0
Discovery meeting	38	7.9
Help with Micro-enterprise	28	5.8
None of the above	139	29.0

Note: Percentages can add to greater than 100 as participants could select more than one response.

Participants were then asked which capacity-building support and resources they had used relating to leadership development and opportunities. Here, mentoring or educating others was most common (32.3%); followed by sharing a story (31.9%) and contributing to community (18.1%).

Table 11: Capacity-building support and resources used by participants: Leadership development and opportunities

	n	%
Mentored or educated others	155	32.3
Shared your story in writing, presented at conferences, group meetings	153	31.9
Contributed to community (e.g. joined a board or committee)	87	18.1
Received sponsorship to attend events	79	16.5
Contributed to political or policy work	72	15.0
Attended a Leadership weekend	64	13.3
Co-designed services or projects	63	13.1
None of these	176	36.7

Note: Percentages can add to greater than 100 as participants could select more than one response.

Across all capacity-building support and resources, information and learning were the most popular. Very few participants (2.3%) had not used any information or learning resources at all. This contrasts with less than a third of participants (29.0%) who had not used any follow up assistance; and over a third (36.7%) who did not engage with any leadership development or opportunities.

The most popular resources in order, across all resource types, were:

- Workshops (75.8%)
- Resources (podcasts, factsheets, videos, publications) (67.9%)
- Webinars (58.3%)
- Websites (54.6%)
- One on one conversation (51.9%)
- Peer networks or discussion groups (47.5%)
- Conferences (46.5%)

Only one of these, one on one conversations, was not listed as a type of information and learning capacity-building.

Not surprisingly then, when asked which form of capacity-building support and resources was most useful, information and learning was the most commonly

selected (44.0%). This was followed by a combination of all three approaches to capacity-building support and resources (38.1%). Follow up assistance and leadership development were regarded as the most helpful by very few participants (4.8% and 1.9% respectively). Only 5.6% of participants regarded none of the capacity-building support and resources as helpful.

Table 12: Most helpful capacity-building support and resources used by participants (n=480)

	n	%
Information and learning	211	44.0
A combination of Information, Follow up Assistance and Leadership Development	183	38.1
Follow up Assistance	23	4.8
Leadership development	9	1.9
None of these	27	5.6

Note: Percentages can add to greater than 100 as participants could select more than one response.

Outcomes for people with disability and other participants

The majority of participants agreed that as a result of being involved with a NACBO organisation they felt more confident (84.2%), learnt and tried something new (80.7%), and felt connected with other people (75.3).

Table 13: Participants who agree that, as a result of involvement with a NACBO organisation, they...

	n	%
Felt more confident	405	84.2
Leant and tried something new	389	80.7
Felt more connected with other people	363	75.3

Participants were asked to select which outcomes had resulted for people with disability as a result of working with a NACBO organisation. They could answer for themselves, as a person with disability, or about the person with disability they support.

The most common response was setting goals for the future, selected by over half of participants (56.5%), followed by 'have more say in life' (54.2%), and spoken up for myself (or themselves) (49.6%).

Table 14: Outcomes for people with disability

	n	%
set goals for the future	271	56.5
have more say in life (choice and control)	260	54.2
spoken up for myself (or themselves)	238	49.6
more independence	206	42.9
taken part in activities or groups in the local community	205	42.7
made new connections and friendships in the community	199	41.5
self-directed funding or supports	123	25.6
attended mainstream education (kindergarten, school or university)	112	23.3
joined a Peer to Peer group	95	19.8
taken up volunteering	87	18.1
created a Circle of Support	78	16.3
moved into own home	77	16.0
participated in civic activities (voting, joined a committee, other)	65	13.5
has a paid job in the community (open employment)	58	12.1
started my own business	58	12.1

Note: 'As a result of working with a NACBO organisation, as a person with disability, I have (or the person with disability I support has)...'

Note: Percentages can add to greater than 100 as participants could select more than one response.

Participants were asked to consider the overall impact of their involvement with a NACBO organisation. Three-quarters (73.1%) said that they had shared new information with others. Just under two-thirds (64.2%) said that they felt more empowered, and over half (54.4%) reported that they have made changes in their life and tried something new.

Table 15: Overall, as a result of involvement with a NACBO organisation...

	n	%
I have shared new information with others	351	73.1
I feel more empowered	308	64.2
I have changed what I was doing and tried something new	261	54.4
I feel my quality of life has improved	193	40.2

Recommending and evaluation of NACBO activities and support

Participants were asked to give an overall rating of the NACBO organisation they have most contact with. Most said 'excellent' (65.6%) or 'very good' (14.7). Only 1.5% rated NACBO organisations as 'poor'.

Table 16: Rating NACBO organisations

	n	%
Excellent	316	65.6
Very good	71	14.7
Good	43	8.9
Poor	7	1.5
Don't know/ not applicable/ no response	45	9.3
Total	482	100.0

Note: Overall, how would you rate the NACBO organisation you have most contact with?

When asked if they would recommend the NACBO organisation they have most contact with to other people, nearly all survey participants said yes (88.0%).

Table 17: Recommending NACBO organisations

	n	%
Yes	424	88.0
No	12	2.5
Don't know/ not applicable/ no response	46	9.5
Total	482	100.0

Note: Would you recommend the NACBO organisation you have most contact with to others?

Appendix E. Evaluation methods

The evaluation was conducted between August 2021 to June 2023. The research took a developmental evaluation approach to inform change during the NACBO program, and measure change and impact to meet the program outcomes. The evaluation study was incorporated within NACBO, using existing information and processes, as well as collecting new data.

The principles underpinning the research include:

- Co-design with project participants, people with disability and family members to inform the research design, findings and dissemination.
- Supporting people with disability to be involved at all stages of the study
- Interviews and stories with people with disability over the life course
- People with disability and family members received a gift card for sharing, writing or recording their stories and interviews in the evaluation.
- Select stories presented in the findings prioritise the voices of people with disability.

The study examined the short- and longer-term impact of the NACBO capacity-building activities on the lives of people with disability and the outcomes that people and families achieved as a result of taking part in NACBO capacity-building, education, follow up and leadership development. The evaluation examined what processes in the project were effective, what challenges remain, how these can be addressed, lessons arising for the Alliance and its governance; and lastly, lessons for the future and policy (Figure 1.2 Program logic).

Overview of methods and numbers

The evaluation used a mixed methods research design. The qualitative data were interviews and stories, written and video stories with and by people with disability and their families involved in NACBO, and interviews and discussion groups with project staff and leaders (Table 18). The evaluation also collected national survey data from participants in capacity-building activities.

Table 18: Evaluation methods and samples

	People with disability, family members	NACBO staff and leaders	Program data
Interviews, group discussion with staff	-	25	-
Stories of change (interviews)*	49		
Written stories	10	-	-
Video stories	3	-	-
NACBO survey participants	482	-	
Participants in capacity-building			Activity data 2020-2021

Note: * 8 people with disability and families were in longitudinal interviews, in 2022 and 2023.

The NACBO [research plan](#) is a comprehensive overview of the study design, questions, and methodology.

The analysis was about the NACBO model, not each of the six member organisations. The quotes and stories in boxes are anonymised with pseudonyms to protect privacy. The direct voice or story of people with disability are prioritised where they are available in the data. Sometimes their story is through their supporters due to their communication support needs or the persons age, in the case of younger children with disability.

Research questions

What is the impact of NACBO

1. What outcomes have people with disability, their families and supporters achieved because of being engaged with NACBO? Which outcomes are not achieved and why?
2. What impact does the NACBO model of capacity-building have on the lives of people with disability?
3. What changes are people experiencing and are people achieving their good life from participating in the capacity-building?
4. What is the impact of how the NACBO model shifts mindsets?

Effectiveness of Processes

5. How does the combination of processes in the NACBO model interlink to change outcomes?
6. What processes are effective in shifting mindsets?
7. What processes are effective to build skills, knowledge and capacity of people with disability and their families and supporters?
8. How are the challenges managed for the model of building capacity and skills of people with disability and their families and supporters? How can these be addressed in the future?
 - Why does NACBO emphasise authentic social inclusion and not segregated options?
 - Why do some NACBO organisations have a focus on families?
 - What is NACBO's rationale for focusing on capacity-building, rather than service provision?
 - What is NACBO's rationale for focusing on building the capacity of people with disability and their families rather than systems?
9. What challenges and opportunities emerged in the NACBO alliance and how can any challenges be resolved?
10. What are the lessons from the NACBO model for future capacity-building?