



An investigation of inclusive sport and recreation in the *My Active Life* Program

A collaboration between Deakin University and the TAD Australia Network

June 2023





The authors of this report acknowledge the Traditional Custodians of the land on which Deakin University campuses are located in Victoria: The Wadawurrung people, the Boon Wurrung people, the Wurundjeri people, and the Gunditjmara people. We also acknowledge the Traditional Custodians of the lands on which services delivered by the TAD Australia Network are located.

This report was developed as part of a commissioned project investigating inclusive sport and recreation in the TAD Australia Network 'My Active Life' program. If you would like more information about this project, please email assistivetech@deakin.edu.au.

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Executive Summary

This report presents the findings of a tendered research project commissioned by the TAD Australia Network. The purpose of this project was to conduct academic research into a \$3.7M program 'My Active Life', secured under the 2020 National Disability Insurance Scheme (NDIS) Economic & Community Participation (ECP) Grant Round. My Active Life (MAL) was initially established as a 3-year program administered by a consortium of TAD state-based providers. Through a range of community-based initiatives, the MAL program aims to improve people's participation and inclusion in sport and recreation activities across Australia. Services delivered within the MAL program include but are not limited to: Inclusive Community Sports Days (where community members can trial adapted sports activities and equipment in their local area); capacity building partnerships with mainstream service providers across Australia; and expansion of the Freedom Wheels program that prescribes and builds customised adapted bicycles to children and adults with disability.

This report delivers key research findings centred on: 1) the personal, social, economic, and environmental context of recreational participation for people with disability 2) the individual and community impacts of MAL-funded programs, such as Freedom Wheels; and 3) the experiences of mainstream service providers in learning about, and providing, inclusive sport and recreation services. Insights gained from this project are presented as briefing documents that can be read and shared individually or collectively. We expect further resources to emerge from this project throughout 2023.

What we did

Each stage of our research has been co-designed with the MAL Lived Experience Advisory Group (LEAG) and National Project Managers of the TAD Australia Network. First, we gathered academic literature, including original research, reviews, and case studies. This helped us to understand the current knowledge base regarding the participation and inclusion in sport and recreation of people with disability across Australia and identify potential gaps in evidence. Then we conducted three exploratory studies of the My Active Life program:

1. A survey to profile the demographics and current recreation experiences of people who are waiting for a Freedom Wheels bike (or other custom assistive technology for sport or recreation), within the MAL program.
2. Interviews with children and adults who use a Freedom Wheels bicycle.
3. Interviews with mainstream recreational service providers who have partnered with the TAD Australia Network organisations in the delivery of inclusive recreation services.

What we learnt

Our mixed-methods research gathered rich insights about the experience of inclusion in recreation and leisure. Importantly, people with disability, their families, and service providers perceived recreational inclusion as more than simply being “present” or physically participating in activities. Being included in sport and recreation meant feeling dignified, respected, and welcome, and inclusion was strongly associated with themes of confidence and identity. Participants described the following benefits to recreational participation:

- Personal growth and development (e.g., becoming more confident; reconnecting with past identity, improved mental wellbeing);
- Social closeness (e.g., spending quality time with friends and family);
- Social capital (e.g., building new relationships; becoming more socially visible);
- Increased independence (e.g., being able to use new skills or assistive technology for more independent mobility);
- Physical health and fitness (e.g., improved strength, stamina, or range of movement; maintaining a healthier weight).

Across our research studies, several factors were identified to affect inclusion. At the individual level, factors relating to the person themselves, such as disability characteristics, motivation, personal preferences, and life experiences, greatly influenced experience of, and engagement with, recreation activities and services. The nature of the activities also had significant influence, including the location, perceived benefits, safety profile, and other participants. Interestingly, at least half of the activities reported in our survey involved therapeutic recreation (e.g., hydrotherapy, exercise physiology) and almost all fell into the categories of sport or physical exercise. This suggests a need to promote awareness of non-therapeutic leisure as a valued recreational occupation. Finally, beyond the individual user and activity context, environmental factors that influenced inclusion included:

- **Environmental accessibility:** Recreational inclusion was impeded by high participation costs (e.g., equipment; entry/lesson/membership fees), transportation barriers, and poor accessibility of built and natural facilities (e.g., narrow pavements or dangerous shared paths that cannot accommodate users of a Freedom Wheels adapted bike).
- **Assistive technologies and adapted equipment:** Assistive technologies and adapted sports equipment helped people with disability to successfully engage in recreation and were viewed by mainstream sports providers as a useful tool for inclusive service provision. Users of Freedom Wheels bikes reflected on specific features about their customised bike that contributed to their own recreational success, including adjustable training wheels, a push handle, and personalised

colours, bells, and baskets. Due to participants' complex needs and support requirements, participants had found the process of co-designing their assistive technology with an expert provider (e.g., an occupational therapist) to be an essential part of this process.

- **Other people:** Most participants across our studies engaged in recreation and leisure with a paid support worker or family member, demonstrating that supporters are important stakeholders in inclusive recreation practice. Additionally, recreation experiences were more successful when community members had a positive attitude towards participants with disability and recognised their potential. Finally, participants noted the importance of constructive collaboration and information sharing between mainstream recreation providers and assistive technology/inclusive recreation specialists.

One important, recurrent theme throughout our research was the cost associated with inclusive recreation. Disability is a risk factor for economic disadvantage, and many participants discussed costs of transportation, equipment, and participation fees as barriers to engagement in sport, recreation, or leisure. Similarly, service providers described difficulties in sourcing and justifying funding for assistive technology or subsidised recreational programs for people with disability, despite their value. Finally, individually customised assistive technologies for sport and recreation (such as Freedom Wheels bikes) are both resource and time intensive to produce and supply, placing strain on under-resourced technology providers. Participants stressed the need for responsive and comprehensive funding models to support the continuation of inclusive recreation services and technologies into the future.

Knowledge Translation

Knowledge Translation is the final step of our research and is ongoing. Our team has shared our research findings throughout the project by:

- Meeting regularly with LEAG members and MAL National Project Managers so that emerging research findings could be translated into current practice;
- Developing inclusive research guidelines based on our work (see *Guidelines for Inclusive Research*),
- Consolidating a set of talking points for TAD employees and LEAG members to share in public, political, and media forums (see *Appendix 2*);
- Including our co-designed research tools in this report (see *Appendix 3*);
- Creating and sharing a public [project website](#) which includes information about inclusive health communication and inclusive research methods.

We plan to share this work as widely as possible, and welcome any feedback from providers, recreational service users or the general community.

Introduction

This research investigation was commissioned by the TAD Australia Network as part of the \$3.7M 'My Active Life' program secured under the 2020 NDIS Economic & Community Participation (ECP) Grant Round. My Active Life (MAL) was established as a 3-year program to be administered by a consortium of TAD state-based providers. Through a range of community-based initiatives, the MAL program aims to improve people's access to, and participation in, sport and recreation activities across Australia.

The research project presented in this report was designed in collaboration with the MAL National Project Managers and a Lived Experience Advisory Group (LEAG). MAL National Project Managers and the LEAG have been actively involved in the co-design of the research aims, recruitment methods, data collection methods, analysis of data collected and dissemination of project findings. The LEAG was established in March 2021 and is comprised of people with lived experience of disability and supporters / carers of people with disabilities (see page 6 for a list of members).

Project Aims

The research project was directed towards three overarching aims:

- Project Aim 1:** To investigate MAL participants' experiences and satisfaction with their Assistive Technology (AT) device & service.
- Project Aim 2:** To explore the impact of assistive technology on participants' participation in sport and/or recreation and/or leisure activities.
- Project Aim 3:** To explore the impact of TAD Australia Network services that aim to enhance the capacity of community agencies to deliver inclusive sport and recreational services for people with disabilities.

This report presents research outcomes generated. Further work on knowledge translation and dissemination of resources emerging from this project will continue throughout 2023.

Methodology

Participatory Action Research

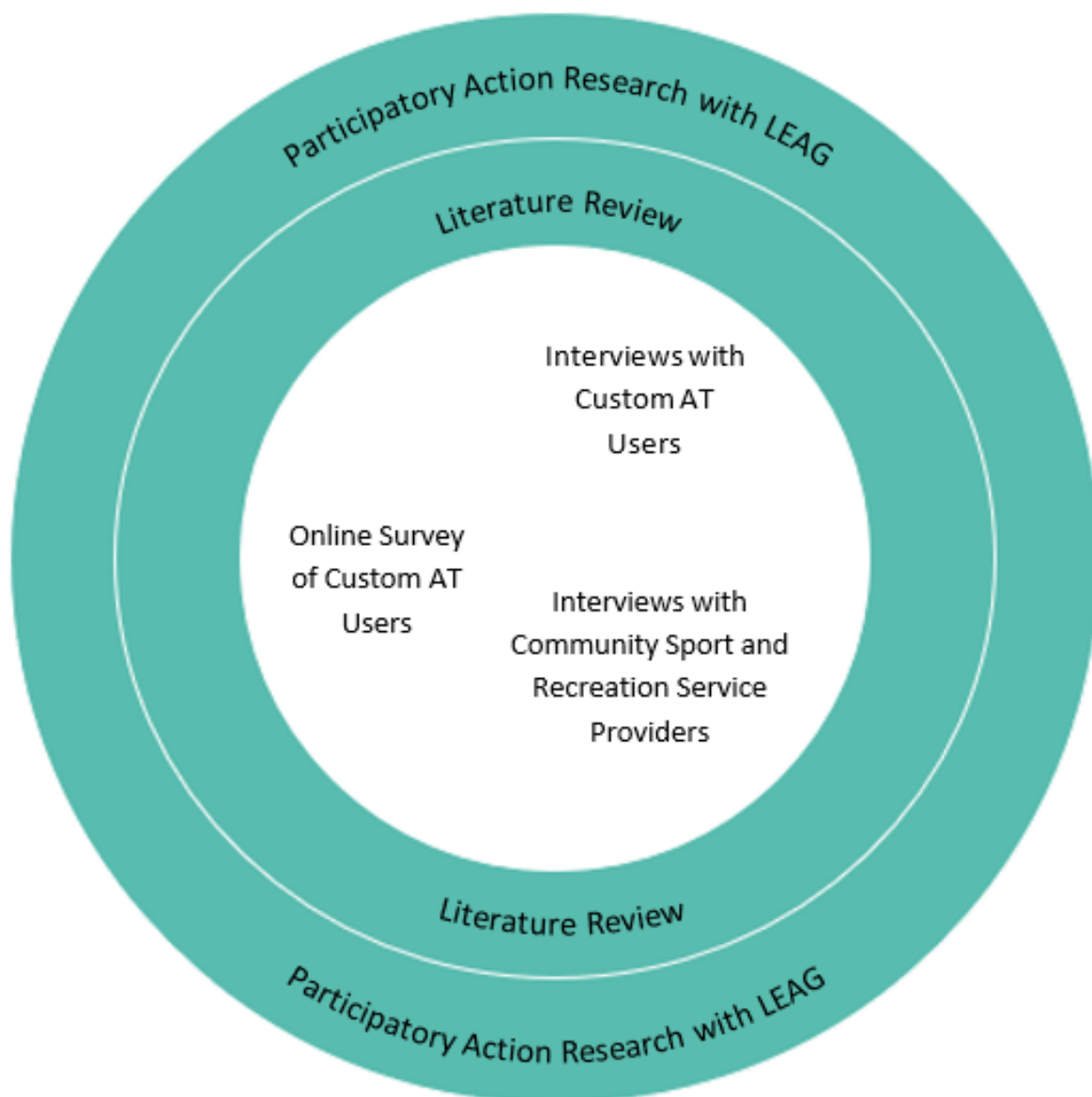
The project's design drew on a Participatory Action Research (PAR) approach. PAR is defined by its commitment to practical impact (action), empowerment (participation), and the inclusion of people with lived experience, such as service users and providers, who engage actively at each stage of the research process. PAR is typically categorised by iterative cycles of data collection, reflection, and action. This project was co-led with a Lived Experience Advisory Group (LEAG), comprised of six people with lived experience of disability and / or who are supporters / carers of people with disabilities. The LEAG and MAL National Project Managers were involved in research planning, data analysis and information sharing throughout the project.

In line with Participatory Action Research, this project was co-designed with a Lived Experience Advisory Group.

Inclusive Research

A range of inclusive qualitative and quantitative methods of data collection were employed to ensure the widest range of perspectives could be represented in study findings. Iterative joint analysis with the LEAG and the MAL National Project Managers ensured that insights from the project could be shared with stakeholders as they emerged. Figure 1 illustrates the iterative relationship between the research activities and how all activities were informed by people with lived experience, industry members, and existing literature.

Figure 1: Overview of project methodology



Project Findings



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Project Findings

Findings gained from this project are presented as briefing documents that can be read and shared individually or collectively. The topics covered are as follows:

- Impact of customised bicycles on people's participation in sport and recreation
 - Vignette of Freedom Wheels User - Drew
 - Vignette of Freedom Wheels User - Charlie
- Perspectives of community sport & recreation providers on delivering inclusive services
- A profile of custom assistive technology users
- Impact of and factors supporting collaboration and participatory design
- Guidelines for inclusive research



Impact of Customised Bicycles on People's Participation in Sport and Recreation

Impact of customised bicycles on people's participation in sport and recreation

Background

Cycling is in the top five most popular forms of physical recreation in Australia (Australian Sports Commission, 2022). Meaningful engagement in cultural life, including sports, recreation, and leisure, is a fundamental right for people with a disability protected by Article 30 of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2007). However, current research suggests that the rates of participation in sport and recreation, including cycling are significantly lower for people who live with disability (Australian Institute of Health and Welfare, 2022). Reasons underlying lower participation rates include a lack of access to appropriate equipment or assistive technology (Darcy et al., 2017). To address this need, there are a growing number of adaptive bicycles available, including handcycles, recumbent trikes, and tandem bicycles (National Equipment Database (NED), 2023). Freedom Wheels is a national Australian program that customises bicycles to meet the needs of individuals with a range of physical impairments. Available features include tricycle frames, outriggers and postural supports that can be modified to suit an individual's needs (Freedom Wheels, 2023).

Adaptive cycling provides people with disabilities a means to engage in this popular activity and experience numerous potential positive outcomes (Angsupaisal et al., 2015; Armstrong et al., 2022; Martinez-Millana et al., 2022; Pickering et al., 2013; Ringenbach et al., 2020). The benefits of adaptive cycling are clear, with research demonstrating opportunity for improvements in functional ability (Armstrong et al., 2022) and fine and gross motor skills (Fletcher et al., 2022). Experiences of improved independence are also commonly reported (Armstrong et al., 2022; Fletcher et al., 2022; Martinez-Millana et al., 2022; Pickering et al., 2013), for example when children with disability are able to ride independently with their peers and family, or adults experience increased independence in community activities, such as shopping (Fletcher et al., 2022).

Despite these benefits, a review of research literature revealed a gap in existing knowledge about how users of adaptive bicycles engage in sports and recreation using their bike, and what factors act as facilitators and barriers to people's use of customised bicycles. Our research contributes toward this identified evidence gap.

What we did

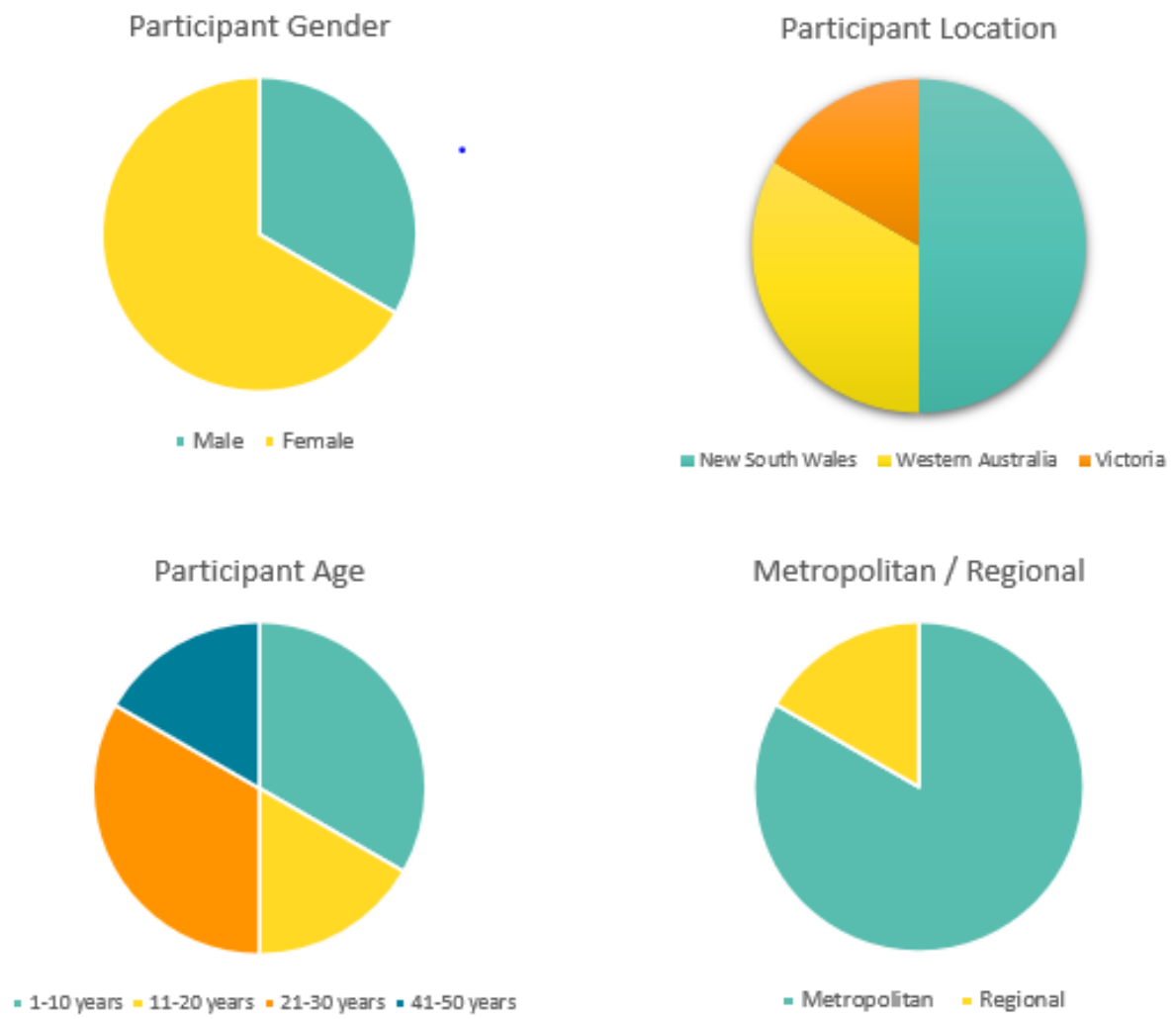
This research aimed to explore people's experiences of engaging with the Freedom Wheels service, how Freedom Wheels bicycles impact participation in sports and recreation, and what factors impact people's use of Freedom Wheels bicycles.

A qualitative participatory research approach was co-designed with the MAL National Project Managers and a Lived Experience Advisory Group (LEAG) comprised of people with lived experience of disability and supporters / carers of people with disabilities. Freedom Wheels users of all ages were invited to participate in this study via semi-structured interviews, photo-voice interviews, the submission of drawings, or via a written questionnaire. This range of options helped to accommodate all Freedom Wheels, users including children, people with intellectual disability, people with lower levels of English literacy and those with digital accessibility restrictions, in the study. Such approaches to data collection have been previously established as effective for these groups (Danker et al., 2016; Dunn, 2017; Mulvale et al., 2016; Shumba, & Moodley, 2018).

Data were collected in 2022 and 2023 and a total of six participants took part in interviews. Five participants elected to take part in an online video interview and one participant chose to provide a written response to interview questions. In five instances, a carer or parent made active contributions to the interview. Interview questions were formatted to ensure questions inquired about the participants' lived experience, rather than the supporters'. As shown in Figure 2, participants lived in New South Wales (n=3), Western Australia (n=2) and Victoria (n=1), were mostly female and located within metropolitan areas. Participants' age ranges were: 1-10 years (n=2); 11-20 years (n=1); 21-30 years (n=2) and 41-50 years (n=1).

As part of their demographic questionnaire, participants were asked to share information on sports and recreation activities that they engaged in, and their role within these activities. The most common activities that participants identified were swimming (n=4), bike rides (n=2) and music (n=2). Other activities included long walks, triathlon, calisthenics, visiting local attractions and nights out with friends.

Figure 2: Demographics of Custom AT Interview Participants



What we learnt

This study offered a number of insights into the scope and degree of impact that an adapted bike had on participants' lives, and the factors that impacted their experience of adaptive cycling. These themes are addressed in detail below.

Freedom Wheels bikes can positively influence people's lives

Participants reported that having and using a Freedom Wheels bike impacted them across a range of domains, including their health, fitness, independence, social engagement, and sense of self.

Fun and function

Riding a Freedom Wheels bike, at its heart, was simply an enjoyable experience for participants. While riding at a park, lake or beach was a popular activity for some, others enjoyed being able to now ride in their neighbourhood close to home. A striking similarity across all the interviews was how cycling brought riders and their family and friends together. As stated by one participant, *"We went away on a holiday recently, last school holidays. We're about to go on another next school holidays. Where we went, they had bike paths which were massive, and we rode every day, my daughter loves it"*.

At times, a Freedom Wheels bike enhanced functioning in daily activities and even competitive sports, allowing for more meaningful engagement in daily activities. As one participant stated, *"We take it to [our local shops] and I also ride it there"*.

Social capital

There was improved opportunity for social capital amongst participants who owned a Freedom Wheels bike. At times this could be with family - *"It's always combined with being with family, with being outdoors and fresh air... with accessing the community."* Another participant shared a feeling of belonging with fellow competitors at their sporting event - *"So I had to put them on and get my bike out and ride. And everyone was riding when I was doing the bike riding."* Some shared how the bike intrigues strangers in public and that this created opportunity for more social interactions - *"He gets people saying 'cool bike'..."*

When I've been out, I put learner plates on it. People say, 'Oh, I want to have a go, can you take my kids?' I'm like 'Hell no, I'm enjoying myself thanks!' You know, I love it!"

Personal development

These positive experiences seemed to provide a confidence boost in participants which manifested in different forms. For one participant it was a sense of normalcy - *"I think it helps reinforce the fact that they can do what everybody else does."*, while another had developed the confidence to talk with people in public - *"... I feel like she's even more confident in kind of engaging with people as well..."*. In other cases, a passion and confidence to exercise had been rekindled once the participant had received their bike.

Independence

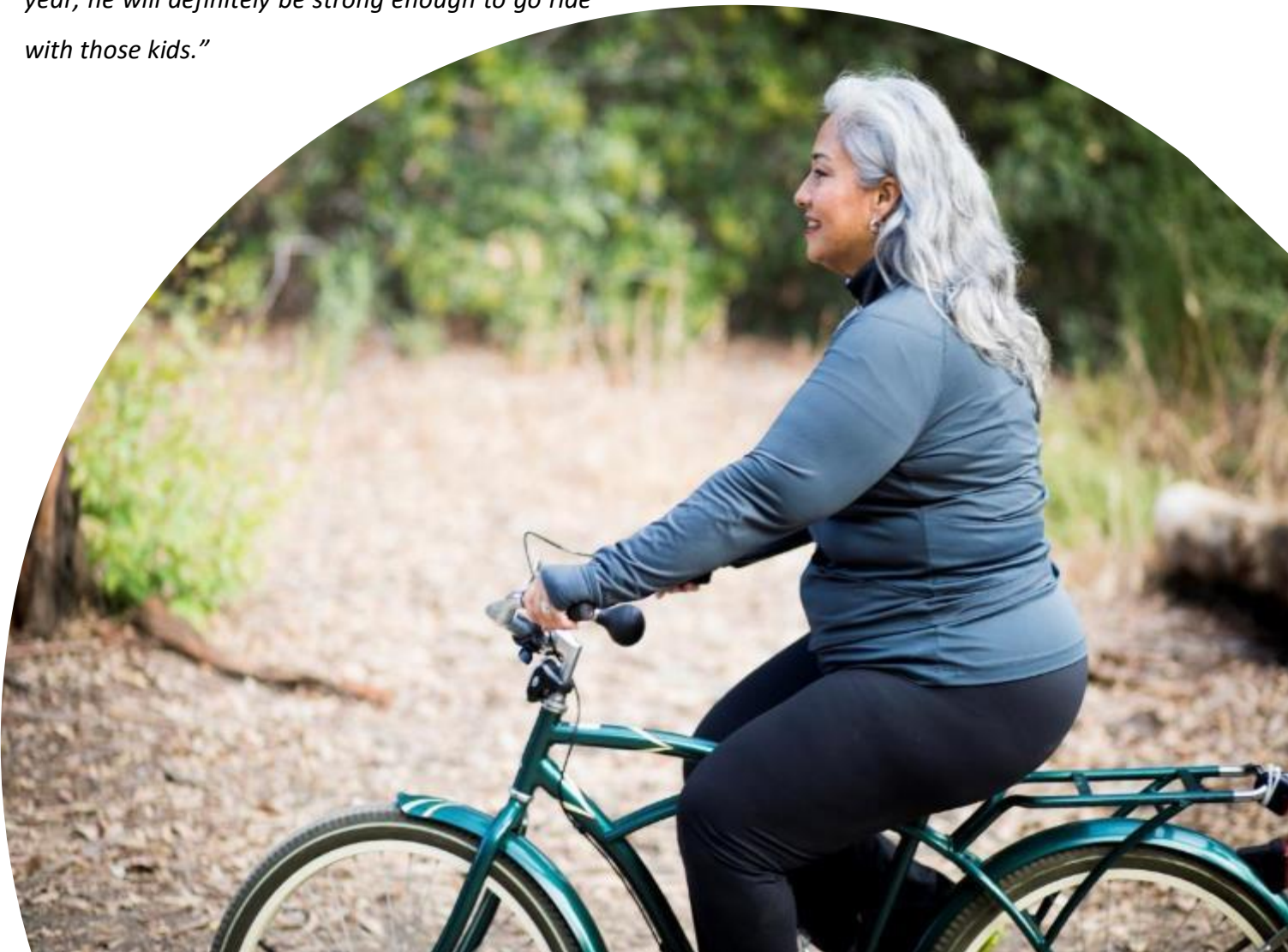
Participants shared accounts of the bike enhancing their independence. This was summarised as having a way to move on their own and being able to ride when they wanted. This was often linked to a sense of freedom. For one young participant, their Freedom Wheels bike offered a meaningful choice in their mode of transport: *"It's given her so much more freedom and choice, ..., even just going, 'do you want to take your wheelchair, or do you want to take your bike?'"*

"Oh! My confidence! I now go and do personal training twice a week. And one day I do with one person and another day, I've increased it now to three times a week, but with a group."

Physical health and fitness

Many participants felt their physical health had improved as a result of riding their bike. For one, the bike provided a means to build their physical capacity, while another incorporated their bike into their exercise, with the goal of building strength, later reflecting, *“My fitness is much better”*. Improvement in strength was reported by numerous participants and was noted to have potential to open doors to new activities: *“... If he continues to ... increase his strength, the school has a bike club. And they ride once a week, and they go out through the bush. And we were thinking next year, he will definitely be strong enough to go ride with those kids.”*

Some participants were keen to expand the sports and recreation activities they engage in since riding their bike. These activities included horse riding, bush-riding, and gymnastics. There was also a rekindling of past exercise goals: *“I'm swimming, and straight away when I got the bike I started to wonder if I could do a triathlon again. You know, I can't run but maybe someone can help me.”*



People's experiences of using Freedom wheels bikes were influenced by a range of factors

Human factors

Freedom Wheels bikes required careful tailoring to riders' physical, cognitive, and other capacities. Participants held valuable lived experience and knowledge of their own needs and valued having their input heard during the bike prescription process.

Activity factors

There was some concern noted for personal and public safety when riding a Freedom Wheels bike and it was suggested that 1:1 safety and riding training could be beneficial. *"We tried originally her going around the main track. That was too difficult to try and that's one thing, it really would have been useful to have somebody who could teach me or teach her directly how to navigate using the bike because being on the main track meant that she could easily swerve into traffic... Or she could go into a normal, you know regular cyclist..., so we then went to the kids' bike track area and that's where she uses it".* One participant felt a tailored tutorial, or instruction manual on how to use the bikes features would have provided a boost in riding confidence.

Assistive technology factors

Some participants and their supporters commented that the bike was quite heavy and was difficult for them to move independently without support. Both supporters and riders commented that the bike's weight was a factor to consider when transporting it in a vehicle.

"Totally! It [a tutorial] totally would have helped me, because I had no confidence and even now, it took me a little bit to go out, every day I want to go out, but I wouldn't go unless my husband was here."

Riders and their supporters commented on numerous features of the bike which they appreciated. Some identified that the adjustability of training wheels lent itself to a longer use of the bike as they could be removed once ready. Other items, such as the basket and the bell, were identified as highly valuable. Younger riders especially loved to keep their belongings in the basket and many also enjoyed the bell as they could *“ring it when people are in [the] way”*. Bikes could also be fitted with a push-handle at the rear of the bike and supporters appreciated this as it helped with pushing a bike when it became stuck. Another supporter felt the push-handle gave them control when needed: *“... at the back of the bike a kind of frame where a person can hold on to the back of the bike in order to steer the person”*.

Participants did share a desire to have further customisation options for their bike, whether that be a choice in colour, some stickers, or some streamers. One supporter stated that this could help to empower the rider further during the process of receiving a bike, while an adult rider wished for more agency in the positioning of key features on their bike: *“... I held on to the handlebars here, right, and down in the middle is where you press the button for electric. I would have probably had it up here next to my hand... Because when I was in there, when I was in the place, the office at Freedom Wheels, they had it like that.”*

One participant described how their bike provides them with stability, allowing them to overcome challenges of balance and feel a sense of security. The bike’s design allowed another participant to overcome environmental barriers and access new areas of recreation. *“... ‘Let’s take the kids out for a bike ride’ - there’s going to be a bit of rough terrain, taking her bike means it can go up curbs, it can go onto sand, it can go onto grass, when her wheelchair can’t”*.

“It is heavy. It'd be better if it was lighter because it is quite difficult to get into the back of a car, or even having something that is a bit more collapsible, because not everybody has a ute or a four-wheel drive”

Contextual factors

Initial assessment and trial typically occurred in a purpose-designed Freedom Wheels trial space, and these environments seemed to instil a sense of confidence and excitement in first-time riders. Notably, the younger participants were drawn to the murals on the facility walls.

“... they open these doors and you’re like in this magical painted - you know what I’m talking about? All the walls have got these sort of cartoon murals on them and then, the floor is customised design... And it was just an incredibly inclusive and positive and fun experience. And it sort of instantly gave her a sense of confidence on the bike.” (Supporter 1)

Supporters and carers were often relied on to provide training and bike maintenance when ongoing services could not be provided. As one supporter recommended: *“In an ideal world if they could send somebody out to help train the person on the bike that would be brilliant, because otherwise it’s left to the family to do that, or to source somebody who can do that.”* Riders and supporters commented on how staff involved in the Freedom Wheels service delivery led to a pleasant trial experience and ultimately a bike that was fit for purpose. Other facilitators relating to staff included their honesty and transparency, and their willingness to go ‘out of their way’ to meet each participant/family’s needs.

The built environment was an important consideration for several riders. One supporter commented on how their area is “hilly” and not an ideal environment for their child to ride a bike around. Conversely, the bike of another participant had an optional electric motor which helped navigate their hilly location. Another supporter commented how footpath width and street furniture in their local community can act as a barrier to the bike’s wider training wheels. However, as per the previous section, bikes could also help overcome previous environmental barriers, such as sand or grass, which previously had prevented access to parks.



Conclusion

As a form of customised assistive technology, Freedom Wheels bicycles offer vast potential to enhance people's participation in sport and recreation, social inclusion, and quality of life. The Human Activity Assistive Technology (HAAT) model is a theoretical model designed to contextualise the many factors that influence people's selection and use of assistive technology (Cook & Polgar, 2020). The HAAT model emphasises that assistive technology solutions are unique to each individual and that the effectiveness of each solution is influenced by a range of human (personal), activity, assistive technology and contextual (environmental) factors (Cook & Polgar, 2020). Findings from this study can be seen to reflect the complexity of assistive technology solutions and that careful assessment of each person's unique needs is essential. Findings also highlight the influence of contextual factors such as service delivery, support, and training as being integral to a person receiving a bicycle that provides real opportunity to enhance their participation in sport and recreation.



Vignette of Freedom Wheels User - Drew

Drew is 10 years old and lives in regional Australia. The past year has been very exciting for them as they have been riding their new Freedom Wheels bike. Drew's bike has so many features they love. It has adjustable wheels to help them balance, a bucket to keep their drink bottle in, a bell to ring and the bike can go very fast.

Drew's parents found it hard to find a bike that could support their feet and balance. Because of this, Drew has had to watch from the sidelines, or have limited involvement in activities their family and friends were engaging in. One of their biggest pet peeves was when their cousins would come over to play. They could play together on the trampoline, but when everyone decided it was time for a bike ride, Drew would be left out. Well, that is not the case anymore!

Drew has spent the past year riding their Freedom Wheels bike at the local park's bike track with their parents, riding on their large property with their sister and cousins and taking part in a competitive sporting event.

Drew's parents feel the bike provides many benefits. They can see an increase in strength and fitness, which will allow Drew to engage in their school's bush bike rides with their friends. It has given them a boost in confidence to try new activities that they never considered before. It has allowed Drew and their family to experience activities in a completely new way with a focus on their independence and inclusion.



Vignette of Freedom Wheels User - Charlie

Charlie is 35 years old and has always enjoyed an active lifestyle, engaging in sports and exercise. However a recent illness meant Charlie could no longer engage in sports or even daily activities like picking up their child from school. Charlie then found out about Freedom Wheels bikes from their Allied Health Professional when asking about different mobility aids. When trialling bikes with Freedom Wheels, Charlie felt the staff were very accommodating and tried their best to understand their needs to customise the bike to be fit for purpose.

Charlie has now been riding their Freedom Wheels bike for a year and has found the bike to be a positive addition to their life. They have now been able to adapt the bike into exercise routines, which in turn has built their physical strength. While the bike has brought a return to familiar exercise, they can now use their bike to ride with their child to and from school.

Previously, the desire to go out into their local community was hindered by pain from walking which turned into a mindset of '*I can't*'. Their Freedom Wheels bike has given them a boost in independence and motivation, where they can go out and explore their local community whenever they please.



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Perspectives of Community Sport & Recreation Providers on Delivering Inclusive Services

Perspectives of Community Sport & Recreation Providers on Delivering Inclusive Services

Background

Stakeholder collaboration is key to inclusive recreation: this includes support services, sporting clubs (Declerck et al., 2021; García et al., 2017; Jeanes et al., 2018; Kitchin et al., 2019; Vanderbom et al., 2018) and children with disability and their parents (Züll et al., 2019). In Australia, exploratory research (Jeanes et al., 2018) indicates that while some clubs actively seek and promote the engagement of people with a disability, they require more financial aid to enhance their inclusive practice. Züll et al. (2019) identified a lack of knowledge around health and sports for children with disability as a barrier to their inclusion in these activities and called on health/sports professionals to promote participation opportunities. Other studies similarly highlight the facilitative role that sport/recreation professionals and volunteers can play in recreational inclusion (Kitchin & Crossin, 2018; Oriel et al., 2018) as long as these personnel are adequately trained to support people with disability (Kitchin & Crossin, 2018; Kitchin et al., 2019; Mooney et al., 2019; Richardson et al., 2017), particularly in high-risk setting such as gyms (Richardson et al., 2017).

While it is evident that inclusive practice can elicit positive outcomes for service users (Kitchin et al., 2019), our literature review identified gaps in this field of research. Notably, we did not identify any research addressing the impact that specialist disability service partners or lived experience experts may have on the capacity of a community sports and recreation provider to deliver inclusive services. Such insights could be used to enhance current and future partnerships, and guide resource allocation within the sector. To address this gap, the following arm of our research explores firsthand perspectives of community-based sport and recreation service providers regarding their partnerships with a TAD service.

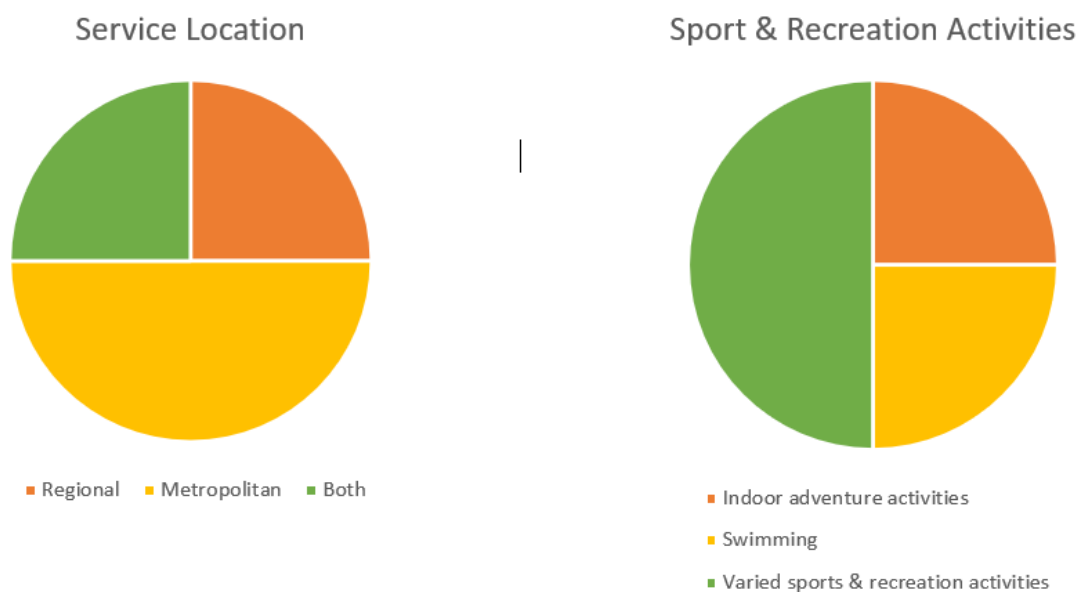
What we did

This research study aimed to evaluate the impact of TAD partnerships on the capacity of community agencies to deliver inclusive sport and recreational services for people with disabilities. We addressed service providers' perceptions of the support provided by TAD services, and their perspectives on recreational inclusion, including perceived barriers and facilitators to inclusive service delivery. To inform related capacity-

building resources (developed by Inclusion Melbourne as part of the MAL program), service providers were also asked about their experiences engaging with the NDIS.

All sport and recreation providers that had partnered with a TAD service as part of the MAL program to enhance their delivery of inclusive services were invited to participate. Four organisations, from Victoria (n=2), Tasmania (n=1) and Queensland (n=1), consented to participate, and an online interview was conducted with a staff member from each. Participants were aged 25 to over 55 years and as seen in Figure 3 provided a range of sport and recreation services in both metropolitan and regional areas. Participants held the following organisational roles: Sports Development Manager, Stadiums Coordinator, Disability Access and Inclusion Officer, and Sport and Recreation Manager. Two participants elaborated on their role, indicating additional responsibilities: instructor and coach, acting centre manager, assistant centre manager and guest experience officer. Participants had worked for the organisation for 3 years (n=1), 5 years (n=1), 9 years (n=1) and 35 years (n=1).

Figure 3: Demographics of Service Provider Interview Participants



What we learnt

Reflections on the partnership

Participants shared varied accounts of how their partnerships developed, some hinting that they were 'discovered' by their local TAD service. Some had been part of a TAD Inclusive Community Sports Day, one partnership was due to a previous acquaintance who now worked for a TAD Service, and another felt their partnership *"definitely came about because they [TAD Service] were looking for a location"*.

"... to deliver activities to engage all abilities participants and disability groups across various regions. The aim is to provide sustainable programs for the target group and encourage regular participation in these activities."

Partnership with a TAD Service enabled the participating sport and recreation providers to offer services beyond those that had normally been achievable. For one provider it allowed the TAD Service to run Inclusive Community Sports Days on site during the school holidays. Another two service providers mentioned how the partnership enabled a monthly All-Abilities group and school holiday disability programs, offered at reduced or no cost to families. Sustainability and increased participation from an existing All-Abilities Group was also reported.

Opportunities for growth arising from the partnerships were different for everyone, with participants expressing a vision for extended collaboration in the future: *"I would like to see us being able to expand it. I'd like to be able to see something happening on a regular basis, weekly, and utilising our centre, and probably the connections that [TAD] has. That would be my sort of next big wish list between us."* One participant suggested extending collaborative services to their company's broader franchise, while another focused simply on embedding: *"regular communication and updates from the partner organisations' coordinators"*. Having experienced successful collaboration with a TAD service, two participants were also interested in securing funding to extend the duration and sustainability of the partnership, particularly around human resources: *"Longer term funding contracts and projects to aid with sustainability of activities offered to participants, and to aid with [our organisation]'s staff retention."*

What are the potential outcomes of partnerships?

Our findings indicate that partnerships between a disability service provider and sport and recreation providers offer several potential benefits for both parties, as well as for end-users of the service. Partnerships had afforded staff *“the opportunity to increase their working hours to deliver more sport and recreation opportunities”*, including low-cost or free activities, increased sessions at more accessible times for clientele with disability, expansion of existing inclusive programs, and the ability to advertise their service during TAD Inclusive Community Sports Days. Regarding the latter, one participant had found that the free Inclusive Sports Day event attracted new clients of all abilities, not just those with disability. Another reported that Inclusive Community Sports Days held during school holidays were a catalyst to host more open day-long activities: *“So we will use *name* and his [TAD] open day as one of our days during the school holidays. But then we'll have our own day as well just building, building on the program that we're sort of starting”*. Finally, one participant explained how the discounted cost of their inclusive activity sessions specifically addressed pitfalls in current disability support: *“The [TAD Service] funding allowed us to run the class at \$5.00 a lesson and cater to many children who could not afford our term-based disability swim classes, which at the time were \$50.00 and were not being regularly recognised by the NDIS for Gap funding.”*

Developing and maintaining an effective partnership was a dynamic process and unique to the individual person and organisation. One participant stressed the importance of meeting in person rather than online, as it allowed for *“many opportunities for questions and collaboration”*. While the ability to discuss accessible and inclusive practice was valuable, it was one participant's passion of inclusive practice which played a key role in networking toward an effective partnership, and arguably the success of their inclusive practice.

Building an effective partnership is complex and unique, offering potential for wide-reaching positive outcomes. As one participant highlighted, some initiatives held mutual benefit for all stakeholders, while others were more altruistic but still valuable:

“... I suppose, of my enthusiasm to bring the diversity, again because that's my role to ensure that we bring everybody into the Centre. So, I have made sure we have always enabled them to come every single holiday. And make sure we have these courts available for them to use”

“... when I hear of things, and I can think of things, and I can make the connections. And it may not necessarily mean that it's going to benefit me. It may not necessarily mean it's going to benefit our organisation. But if I know that this particular group would work with this particular group, and the, the connection between them and I'm talking everything. I'm talking right across the board. Not just necessarily you know the all-abilities, it's basically everybody”.

Partnerships were fruitful, but participants still reflected on what could be improved. Funding availability was a common theme and participants reflected needs raised in other arms of our study: “[We need] external funding sources to be able to keep the price of lessons down and expand the amount of lessons. We currently have a waiting list of 10+ people without the teachers or funds available to currently cater for them.” Another participant described tensions around the individual versus broader impact of funded interventions: “You know it's a few thousand dollars to get this harness. Then we think about how many numbers of customers will actually use that in the years - not many. So, it's the justification of spending that cash on that particular tool, when you can still deliver [a service] to people without it.” Participants shared varied experiences with the NDIS, however there was a clear desire to understand more about how they can use it to better serve their clientele.

While not directly related to partnerships, some participants shared accounts of how they engaged people with disability in their workplace as a paid staff member or part of a work-experience program. These decisions were reported to have been a positive experience for all involved, leading to enhanced social interactions and camaraderie, improved confidence for the worker with disability, and in some cases forming a pathway to paid employment. One participant recalls the impact that work-experience had on one person with disability: “He's actually moved on to working in a café now. We've brought...him out of his shell. We gave him a bit of structure that it took a while for him to accept”. Workplace flexibility was seen to be imperative, for example offering a worker a combination of on-site and work-from-home conditions or collaborating with a case worker to develop individualised communication assistive technology for a person completing work experience. While affirming the importance of flexible working conditions, another participant found that their employee relished the social aspect of in-office work: “... because he likes the social aspect as well, so he'll drive here usually on a Thursday. And do an 8-hour shift on the Thursday.” Given the importance of lived experience to the design and delivery of inclusive services, these insights may guide the growth and support of an expert lived-experience workforce within the sport and recreation sector.

Conclusion

Partnerships between TAD organisations and sports and recreation providers are unique, dynamic and offer benefits to all stakeholders. This research illuminates factors that support improved collaboration, which may help shape organisational practice guidelines for similar partnerships in the future. It is important for supporting organisations like the TAD Australia Network to realise there are many ways to target support and that flexibility is valued. During the interviews, participants highlighted adjacent areas of practice that may benefit from partnership input, such as the employment of people with disability in their services. They also emphasised a dire need for additional funding, particularly to staff additional classes and activities.



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A Profile of Custom Assistive Technology Users

A Profile of Custom Assistive Technology Users

Background

People with disability who regularly engage in sport or recreation enjoy a range of physical, mental, and social benefits as a result (Arslan, 2014; Aytur et al., 2018; Kerr et al., 2012; Lundberg et al., 2011; Schmid et al., 2019; Teveten et al., 2017), and recent literature shows that many Australians with disability are active and enthusiastic participants in sports, recreation and leisure activities (Hassett et al., 2021). While Australians with disability are engaging in physical sports and recreation, recent cross-sectional research on adults' leisure and physical activity found that overall people with disability were less physically active than people without disability (Hassett et al., 2021). Hassett et al., (2021) found that 78% of adults with disability had engaged in sport or physical recreation once or more in the past 12 months, when compared to 91% of adults without disability. Both groups of people who engaged in sport or physical recreation were more motivated to try a new physical activity that may benefit their health, but poor health or injury was a significant barrier to participation in sports and recreation for 62% of people with disability surveyed (Hassett et al., 2021). Our own qualitative research on the impact of Freedom Wheels bicycles on people's participation in sport and recreation shows that people with disability who use assistive technologies may experience significant challenges in the recreational arena (see Briefing Document *"Impact of Freedom Wheels Bicycles on People's Participation in Sport and Recreation"*).

Despite the complexities of serving these populations, little is known about the specific needs and experiences of assistive technology users in relation to sport or recreational engagement. To address this gap, this section of the report presents the findings of an online consumer survey that aimed to profile the demographics, recreational engagement, and health service use of My Active Life participants.

What we did

The research team developed an online, exploratory survey to be completed by MAL service users. In line with a participatory research approach, an iterative co-design process was employed, and input was received from the MAL National Project Managers, MAL Steering Committee, LEAG Members and Dr Jerry Lai (Analyst, Deakin eResearch) during the survey design phase.

Potential participants were identified via the Custom Assistive Technology and Freedom Wheels waiting lists in each state, with the assistance of local staff. State staff either directly emailed an invitation to

eligible participants or included information about the survey in a broader orientation email for the service. Instructional videos and flyers were also provided by the research team to assist with recruitment. Eligibility criteria included:

- Currently on the waiting list to receive a Freedom Wheels device or custom assistive technology;
- Technology need was associated with a recreation, sport, or leisure goal. For the purposes of the study, 'recreation and leisure' were defined as per the World Health Organisation's 2001 definition: "engaging in any form of play, recreational or leisure activity. Examples include: casual or organised play and sports; programmes of physical fitness; relaxation; going to art galleries, museums, cinemas or theatres; crafts or hobbies; reading for enjoyment; playing musical instruments; and sight-seeing, tourism, and travelling."

The survey was administered online and included:

- An information and consent form;
- A demographic questionnaire;
- A custom-built questionnaire on satisfaction with recreation;
- A custom-built Resource Use Measure (diary) for recreation and leisure engagement (see Appendix 3);
- A custom-built Resource Use Measure for health service engagement;
- A modified version of the AQoL 4D Assessment of Quality of Life.

MAL service users could complete the survey themselves or have a proxy supporter complete the survey on their behalf. Tailored, accessible forms were available for each completion mode, and piping was used to further customise the survey for each participant.

What we learnt

A total of 13 people completed the profile survey. Eight were on the waiting list for a Freedom Wheels Bike and five were waiting for other recreation-focused Custom Assistive Technology. Nine participants completed the form on behalf of an AT user, and the remaining four surveys were completed by the user themselves. Nine users reported living in a city area, and 4 in a regional location. Only 5 participants responded to the question asking if they had ever attended an Inclusive Community Sports Day (a.k.a. 'Come and Try Day'), with four answering no and one answering yes.

Quality of Life

Seven participants completed the Quality of Life (QoL) assessment. We have chosen not to report overall Quality of Life (QoL) scores for several reasons:

1. This metric was intended as part of a larger economic evaluation study for comparison purposes only;
2. The questions in these standardised tools are not defined by people with lived experience. Discussions with Lived Experience Advisory Group members, in addition to broader literature on QoL evaluation in people with disability, suggests that the individual components of these tools (e.g., dependence on care, physical or sensory ability) may not reflect the quality of life values held by this population;
3. Co-designed modifications to the wording of this tool, to improve its readability and inclusiveness, impacts the validity of comparisons to population norms;
4. Given the sensitive nature of questions in the AQoL 4D, we gave participants the option to skip or provide an alternative answer to questions they did not feel comfortable about. Some participants did choose to complete some questions, impacting the validity their total score.

Instead of reporting on the overall QoL metric for this group, we have highlighted three interesting trends we saw in these data.

- All participants required at least some assistance with household tasks.
- All participants described experiencing a moderate amount of pain/discomfort, and all but one reported experiencing some degree of anxiety or depression. However, considering the timing of this survey, the latter finding may reflect the increases in mental health burden seen across the mainstream community in Australia during the active COVID-19 pandemic periods.
- Five out of seven participants reported warm and close relationships with family and close friends, but five out of seven also reported feeling some loneliness in their broader community.

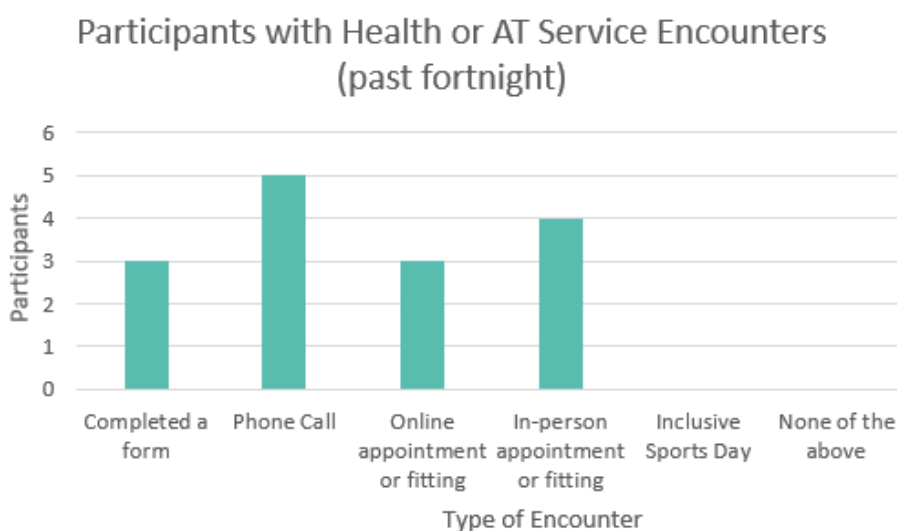
Income and employment

When asked whether the AT service user was currently in employment, eight reported no, two reported yes, and three respondents chose not to answer. For those who were employed, fortnightly income (when reported) ranged from \$0 to \$2500+ per fortnight, with 30% earning less than \$500 per fortnight. While we did not collect data on total household income, these data indicate that participants may have been earning individual income below the defined poverty line for Australia (\$489 per week for a single adult).

Health Service Use

Eight surveys included data for fortnightly health service use. Figure 4 shows all respondents reported at least one encounter with a health or assistive technology service in the past fortnight, with phone calls being the most common type.

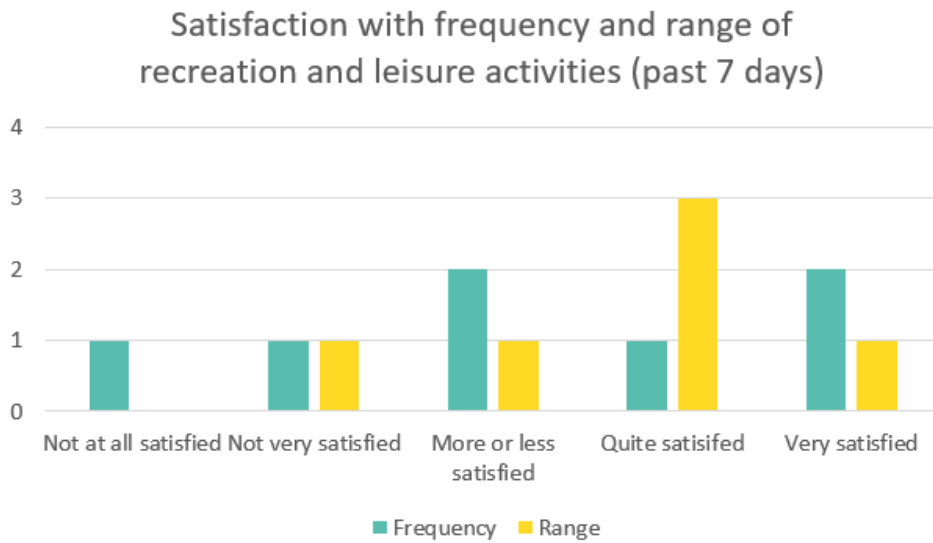
Figure 4: Participants with Health or Assistive Technology Service Encounters (past fortnight)



Satisfaction with recreation and leisure

Seven people responded to the questions about satisfaction with their recreation and leisure participation. Figure 5 shows that only 5/7 were satisfied with the frequency of engagement in recreation and leisure activities over the past two weeks, and 6/7 were satisfied with the range of activities they had engaged in. Commonly reported barriers to participation included mobility difficulties, fatigue, infection risk, and equipment challenges (e.g., having a right-hand drive wheelchair despite being left-handed, or having the requirement to bring additional equipment, such as large prams and portable oxygen concentrators).

Figure 5: User Satisfaction with frequency and range of recreation and leisure activities (past 7 days)

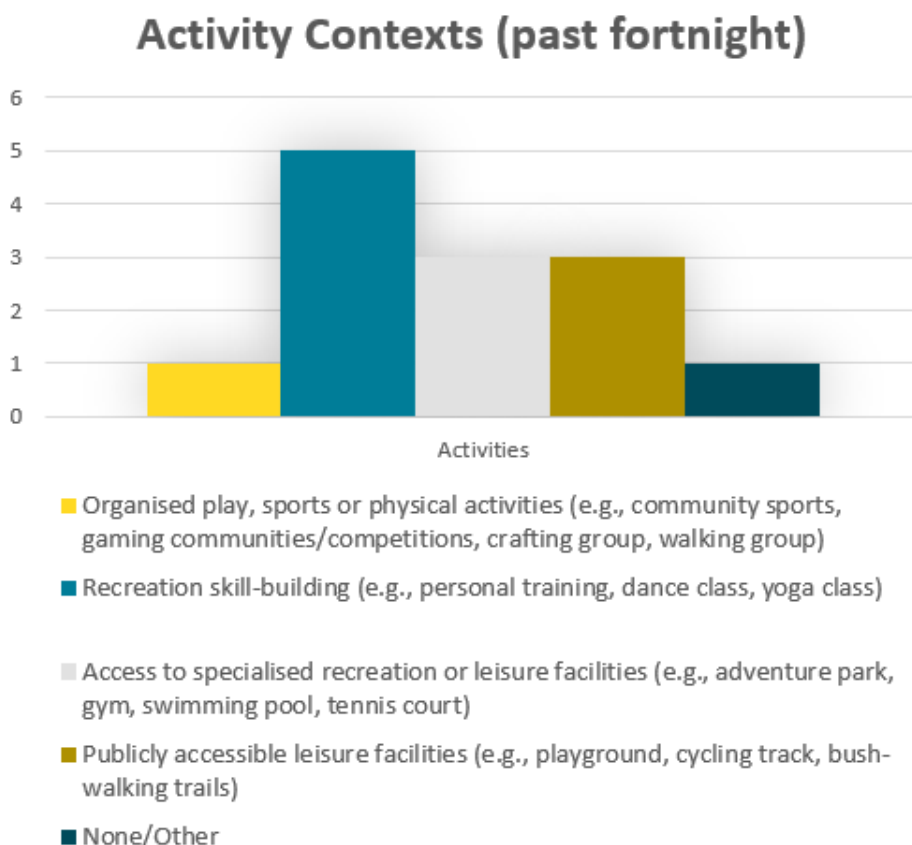


Recreation service use

Seven participants reported on the recreation and leisure activities they had participated in over the past fortnight, with a total of ten unique activities reported. Participants repeated some activities up to 6 times within the fortnight, resulting in a total of 26 activity instances logged.

Half of the activities involved recreational skill-building (e.g., personal training, hydrotherapy, physiotherapy, supervised upper-limb strengthening, and working out on cycling and walking machines). Tennis and cycling were also reported. Reasons stated for engaging in the activities were mostly focused on physical benefits including personal physical health and wellbeing, or specific goals such as *“hand therapy”* or *“my son is obese”*. One person noted that spending *“time outdoors”* was an additional reason.

Figure 6: Activity Contexts (past fortnight)



In one instance the person with disability participated alone, and in two instances they participated with a friend/family member. In the remaining eight instances participants were accompanied by a paid support worker. Participants typically accessed their activity by private car (n=8; 80%), and two participants reported walking/cycling to the venue. Participants travelled between 1 and 36.8km to attend their recreation activities, with an average travel distance of 9.3 km.

Costs of participating: time and money

All ten activities were reported to take 30 minutes to complete. However, total time invested in the activity ranged from 30-120 minutes (typically 60 minutes: 63%). In all instances, the person with disability and their family/friends did not receive pay or compensation for the activity. 90% of the activities were reported to have no out-of-pocket expenses (excepting transportation costs), with seven instances (70%) fully covered by the NDIS. In one instance a cost of <\$50 had been self-funded. One participant had also made use of leisure facilities at a retirement village, which entailed paying a membership fee.

Conclusion

This was a very small profiling study. Consequently, we cannot claim that the population sampled is representative of the broader population using My Active Life services. This study also required participants to self-enrol in the survey, which may have led to an under-representation of certain populations such as those with significant work or caring responsibilities. Additionally, we are aware that recruitment was more successful in some states (e.g., NSW and Victoria) than others, which may limit the generalisability of these findings.

Despite these limitations, there are some findings from this survey that present interesting considerations for practice change and suggest a need for additional research. These include:

- Half of the recreation and leisure activities recorded in this survey were therapeutic (rather than community-based) and were NDIS subsidised. This demonstrates the value of NDIS funding for improved recreational engagement, but also suggests a need to encourage individual planning and funding for broader recreational and leisure activities beyond therapy and fitness.
- All participants in this survey reported considerations for accessibility, which included fatigue, pain, mobility or self-care support needs, and the use of bulky equipment. To improve accessibility of sport and recreation facilities, providers can refer to the following guide from Sport and Recreation Victoria: [Planning for Universal Design](#).
- Almost all activities were attended by at least one paid support worker, family member or friend. Given this, we urge services to adequately accommodate for supporters and attendant carers as important enablers of inclusion. This includes accepting companion cards and providing adequate facilities for carers to undertake their work (e.g., chill-out/sensory areas, comfortable observation/waiting areas, and accessible bathroom and changing facilities such as a [Changing Places](#) room).
- Utilisation of free or low-cost public recreation and leisure facilities was very low. We are not able to speculate on the reasons behind this, but a targeted review of the location, accessibility, and inclusivity of public recreation spaces within specific local areas may provide further insight. The [Everyone Can Play](#) website offers valuable guidelines to creating inclusive public playspaces.
- Our economic survey suggests that a cohort of MAL service users are likely experiencing poverty or financial hardship. Economic burden and outsized employment disadvantage for people with disability is well recognised (Davidson et al., 2018). To counter this, service providers should work to minimise the out-of-pocket costs incurred by participants with disability, including those relating to transport, attendant care, activity registration and membership, and the cost of equipment. From our

interviews with service providers, we are aware that such financial accommodations may require Government or philanthropic funding support. Anticipated recreation costs should also be addressed in the course of an individual's NDIS planning where available.

- Participants reported good relationships with close family and friends, but many felt somewhat lonely in their broader community. Building on our current qualitative findings, future research could explore the potential for recreation and leisure to combat isolation in at-risk cohorts of people with disability. Finally, when setting goals around social inclusion (e.g., in the context of NDIS planning), the potential role of recreation and leisure activities should be considered.

Future Considerations

Some data from the survey could not be reported due to smaller than expected recruitment numbers, particularly for post-delivery AT service users. Additionally, due to smaller numbers evaluative analyses could not be performed, such as evaluating satisfaction with Freedom Wheels bikes or Custom Assistive Technology, or comparing health, AT or recreation service use, quality of life, and economic outcomes before and after customers received their technology.

If large-scale evaluation surveys are to be undertaken at TAD services in the future, the following steps, while resource-intensive, may help to optimise the recruitment performance:

- Allocating resourcing for a staff member to send personalised emails or make phone calls to all eligible service users, alerting them to the study;
- Client-facing staff could discuss the study with all eligible clients and provide links or paperwork as necessary. This may require some additional time during scheduled sessions, or additional capacity for administrative staff;
- Employing a research assistant or allocating a staff member to help clients (especially those with language barriers or technology access difficulties) to complete their survey in person or via phone;
- Providing individual payments for survey completion, rather than a lucky-draw approach.

Based on participant responses and gaps in the current survey, the following measures would be worth prioritising in future surveys:

- Engagement in recreation and leisure activities (type, location, costs and funding, satisfaction) – pre- and post- delivery of technology (see Appendix 3).
- Satisfaction with assistive technology following delivery.

We do not recommend the use of Quality of Life or financial measures in isolation, however the adapted forms of these tools may be valuable in the context of a broader economic outcome evaluation, should recruitment barriers be resolved.

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Impact of and Factors Supporting Collaboration and Participatory Design

Impact of and Factors Supporting Collaboration and Participatory Design

Background

Effective and inclusive collaboration with people with disability in research is an intricate practice. Researchers and service providers who engage in collaborative practice describe a range of strategies that can foster meaningful inclusion of people with disability in research, such as upskilling co-researchers with disability to be able to perform essential research tasks (Hollinrake et al., 2019; Jennings et al., 2018; Rochette et al., 2022). For instance, Hollinrake et al. (2019) trained researchers with disability to conduct interviews with other people with disability while in the presence of two academic team members. The team observed that researchers with lived experience built a stronger rapport with interview participants through the genuine empathy they could share.

Adequate training for co-researchers with disability is important for ensuring their meaningful contribution, as is understanding the unique capabilities of each research team member when assigning tasks (Embregts et al., 2018; Schwartz et al., 2020). Further, research teams must consider the continuing resources or assistance that co-researchers will require, citing flexibility and accessibility of resources and research tasks as key (Schwartz et al., 2020), and be mindful that the fast pace of academic work and use of academic language, especially abbreviations, may not be comfortable or accessible for team members with lived experience of disability (Embregts et al., 2018).

Leaders in collaborative research advise teams to listen to researchers with disabilities and address their unique participation needs (Stevenson, 2010; Jennings et al., 2018; Robinson & Notara, 2015; Terrill et al., 2019). This tailored support is likely to require frequent engagement with co-researchers, including meetings (Jennings et al., 2018; Robinson & Notara, 2015; Terrill et al., 2019). Bigby et al. (2014) also warn that organisations and researchers (including co-researchers with disability) will need sufficient time to prepare for inclusive engagement.

Alongside inclusive practice during the 'work' stages of research (e.g., data collection, data analysis, and recruitment), several studies have examined the collaborative processes involved in acknowledging and documenting the input and impact of co-researchers with lived experience (Jennings

et al., 2018; Mulvale et al., 2019; Stevenson, 2010; Terrill et al., 2019). Mulvale et al. (2019) describe this as ensuring research team member input is not simply tokenistic, and that the research team is able to demonstrate to the researchers with a disability how their input has been implemented, and the potential impacts of this input.

Having worked together for almost two years, the Lived Experience Advisory Group (LEAG) and the Deakin research team collectively decided we would like to explore and document our experiences of collaboration. These insights are shared below to encourage the wider adoption of participatory research methods in sport and recreation research, and as a resource for other teams embarking on participatory work.

What we did

We interrogated our own experiences as a group through a combination of methods including document review (meeting agendas and minutes), a reflexive focus group, and a collaborative analysis and writing process. The focus group was comprised of the Deakin research team (n=6), LEAG members (n=6) and a TAD representative (n=1). To prompt individual reflection, all participants were sent a Mentimeter link where they could answer some preliminary questions, prompting reflection and outcomes. This preliminary input would be used as discussion points during the focus group. A research team member led the discussion, allowing for the conversation to occur naturally. The focus group was audio-recorded and transcribed. The data were then coded into initial themes with relevant quotes. These themes were shared with the Deakin research team and LEAG members for co-analysis. Themes were coded into NVivo (QSR International) in preparation for dissemination.

What we learnt

Several themes were identified during the reflexive process, regarding the factors that made our collaborative research efforts successful. These included the disruption of power, cultivating an open atmosphere, social dynamics, and the valuing of diverse lived and professional experiences. Collaborative research expectations, processes and the translation of knowledge were also discussed.

Disrupting power structures

Disrupting power structures was a strong theme making numerous appearances, though unique to the individual. One researcher appreciated the group's approach of being open to what the project could look like. A LEAG contributor expanded on this notion:

"I think the ambiguity has really served us well. We were a bit like, well let's bloody do it. You know, and so really there was no expectations because we just didn't know where we're going

so, then I think that's what made it really open as well, because we were just like - we will trial this, what about that? Well, I don't know, how do we feel about this?"

The Deakin research team and LEAG worked closely together, sharing power when designing the various research tools and protocol. This was not lost on one LEAG contributor: *"I saw that there were still open discussions about how we can mend it or how we can bend it"*. The Deakin research team also realised the potential to push current boundaries in research accessibility, fuelled by the group's level power dynamic: *"... the second part of the research project is the interviews that we're conducting with people and, what did you say [LEAG member name], really just ..., 'go rogue'. That was the phrase that you used: 'Can we go rogue in terms of how we allow people, enable people to participate?'..."*

From one researcher's perspective, the team's openness to share power around the design of research tools and protocol could have been more clearly established from the beginning, as this may be a trait not all researchers would be comfortable or familiar with, or that all community collaborators would immediately expect. *"... we didn't say to you: 'we're not your traditional researchers, yeah you can embrace the chaos, yeah just go with it... we're just going to see what comes...'. That's, something we possibly next time I think you know, set that scene."*

Open atmosphere

Members from both the LEAG and research team appreciated the open atmosphere, noting it was *"Okay, to be who I am"*. Our group's atmosphere provided comfort and became a place where we could openly learn from each other. Insight into the partner organisation's practice was a helpful outcome of this atmosphere, with a research team member recalling that when it came to grassroots knowledge and context, *"everything that we do when we're planning the research takes that into account."*

A potential contributor to the open atmosphere was the flexible leadership style of the MAL National Project Manager. This flexibility allowed research project members to *"... evolve, and suggest, and push a bit, because you [project manager] didn't have a set leadership direction and that's good"*.

Group social dynamics

The openness of the group led to meaningful changes, learning, and a welcoming environment. Reflecting on our time together, members found the group *"... just challenged my own prejudices"* and that they had *"... absorbed and learned so much"*. One LEAG contributor beautifully summarised the scope of the LEAG's social connections: *"... we have a purpose, we got some synchronicity going on"*. However, these group dynamics only evolved with time, with most members agreeing we started out quite formal, and over the course of many meetings transformed into the dynamically vibrant partnership that made the project.

Everyone's lived experience is valued

It was the combined lived and professional experiences of all group members that ultimately fuelled its success. Everyone, with or without disability, brought their own perspectives and experiences into the research, and the project team believed this intersectional richness should be valued. *"... They bring their worldly skills, and you know there's a lot more that a person can contribute [aside from their disability identity]."*

One LEAG member shared a story of their personal experience in both using assistive technology and working in the disability field, typifying the complex intersections of expertise that existed across the team. Several LEAG members and researchers also shared common experiences of being a family member of a person with disability. Indeed, the group's philosophy of questioning everything, which was lovingly described as *"going rogue"*, was borne from one LEAG member's experiences of being the parent of an autistic child: *"... I think some of that comes from being a parent of a person with autism. Because the way she processes information is very different... she questions everything, including me"*. A background in sports management assisted another LEAG member in engaging with the project's complex data *"... I know how to interpret it, and maybe undertake that process to get more impact or getting an outcome from that data ..."*.

LEAG members experiences and perceptions of research

Members of the LEAG entered this project with differing views and past experiences of research. It was clear these shaped their perceptions of research and what being part of the project might entail. *"I had to remind myself to stay open just let them lead it, they're the researchers and hopefully it won't have the same outcome [as past projects]"*. Perceptions of research had also led to an increase in hesitancy to engage in a research project: *"Because for research I normally run the other way."*

LEAG members had held varying expectations around being part of the LEAG. These ranged from general uncertainty about research or the MAL program, to uncertainty in what they may be asked to individually contribute. While the group's social dynamics were previously mentioned as a key factor in making the LEAG work, participants still felt on

"I feel you know started off... kind of straight to business at the start, you know we're here, what are we going to do, but over time it's become much more relaxed, and I feel like it's because we've all gotten to know each other a lot more".

the outside at times: *“I’ve always felt I’ve been on the outer, to be honest, of this group. Because I felt like a lot of people were somehow connected to Solve. I thought the lived experience people had a previous connection to Solve... I didn’t know what anything was to be honest...”*.

Outcomes of the LEAG

It is clear the LEAG’s combined experiences and perceptions had a profound impact both on, and beyond, this project. This included impact at the personal and organisational levels through the transfer of knowledge across various settings. As one LEAG contributor explained: *“[the group] has been instrumental in making that common sense - so uncommon - making it common again”*. For example, this return to “common sense research practice” was key in the development of an accessible interview schedule, which ended up being centred on one core question: *“I remember vividly, spent like an hour nutting out these complex interview questions... I can’t remember who it was, said that basically it’s just like: ‘what is life like with a bike?’. And that question ... it came from the discussions that we’ve had”*.

The learnings gained from the LEAG did not just stay within the realm of the research but was observed to travel throughout the TAD Australia Network, reaching the “Steer Co” (Steering Committee) and the “operational parts of the business”. Lived experience feedback provided grounding for operational negotiations: *“... we got a bit of push back on that didn’t we? ‘Come and try’, we won’t call it ‘come and try’ and I said we’ve got a LEAG for a reason - they told me not to call it that. So you wanna keep calling it that? Knock yourself out. But I’m just telling you that the people behind us that we’ve asked said it’s a bit patronising.”*

Similarly, the LEAG’s knowledge also gave weight to the researchers’ arguments when they were negotiating with the University’s Human Research Ethics Committee, particularly around any accessibility modifications that Ethics reviewers saw as unconventional or potentially risky.

“If I approached the ethics committee and they pushed back on something that actually just makes ...good, practical sense, it’s going to improve the experience of participants... It makes such a difference, to able to say research participants, consumer advisors, consumer partners, co-researchers have told us that this is what they want. And it leaves very little room for universities to kind of push back against that”.

Transfer of knowledge gained from the LEAG

All members discussed how their time working on the project had influenced their professional work. For example, the group experiences had shaped how one LEAG member now encourages their workmates to consider differing points of view: *“... to continually remind them to just look at things differently”*. Transfer of knowledge to the workplace was also seen in personal work practices:

“Being part of this group and how the research team goes into the details of every word, every pause, every comma and what would make what difference. That’s what I’m taking away in the last two years. I have been very more mindful of what I speak, and what words I choose”.

The transfer of knowledge also had significant impact for the research team. Reflecting on the learnings gained, one university researcher reported a shift in worldview, with resounding transfer of knowledge to numerous individuals outside of this LEAG: *“I think that they’re influencing [our] supervision of [student’s] project greatly, and the approach that we’re taking. I’m doing my PhD at the moment, it’s influenced greatly how I’m looking at what I’m doing. And beyond...”*

The Deakin research team valued the sage wisdom granted by LEAG members during meetings: *“This is so useful for us. We would debrief after it and go wow! It blew our minds”*. Debriefing and knowledge translation for the research team also extended beyond internal discussions, when they shared insights and resulting recommendations with other research teams.

Knowledge on what this team has achieved has also been shared in a range of formats. The accessible online survey is be shared in an online repository for other researchers wishing to engage participants with a streamlined, accessible survey. In addition to this, the group have talked about other ways they plan to share our experiences with audiences outside of the academic community, for example using podcasts, story-telling, and a *“... one-page statement how this group has helped a person’s life”*.

“I probably mention the work that we do at least once a week, so other people other researchers people in policy... I talk about you know, about working with an advisory group we’ve found these things or you know. That’s... a pretty big outcome...”

Conclusion

A collaborative approach was beneficial to both the research team and LEAG members. The findings from this reflexive study paint a clear picture of outcomes that not only influenced this project but transferred to other domains of professional, personal and academic life. By sharing these learnings, we hope to encourage other organisations who are working with people with disability to engage with a LEAG or other forms of consumer partnership. These findings also show how established research approaches, methodology and standardisations may not be relevant to people with disability, and how a LEAG can provide strong justification for necessary amendments. To assist other teams, we are pleased to provide a set of practical guidelines for inclusive research as a component of our main project report.



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Guidelines for Inclusive Research

Guidelines for Inclusive Research

Introduction

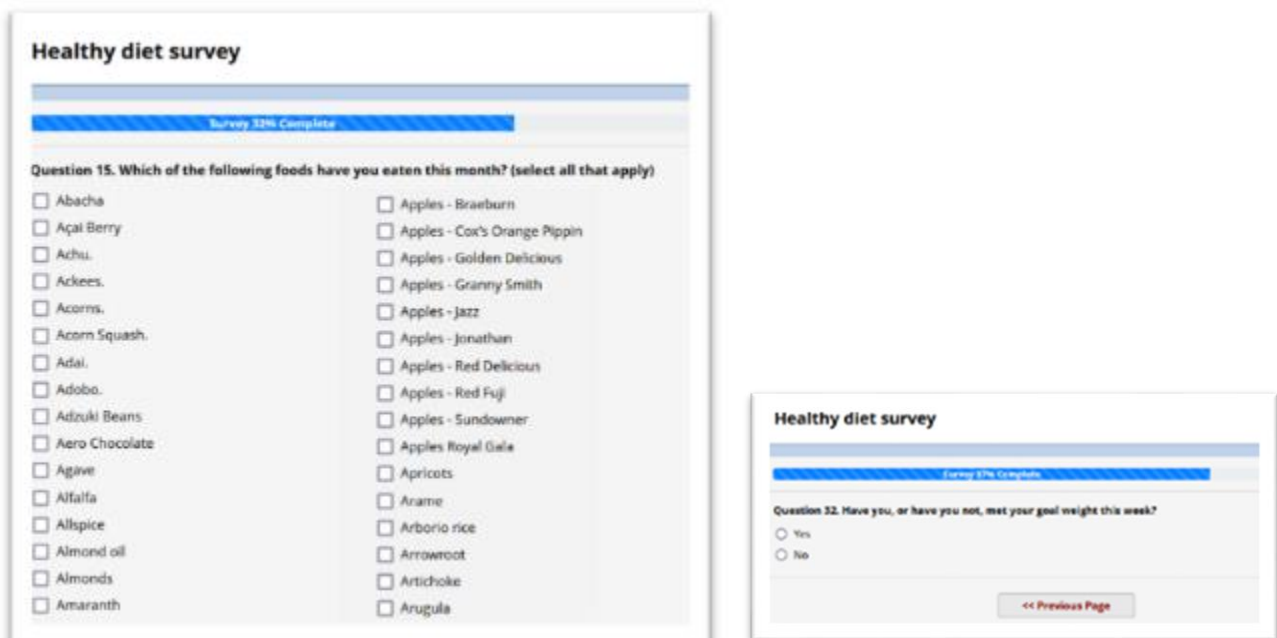
This project has provided many insights into what makes assistive technology research inclusive, feasible, and successful. An important aspect of this is working in partnership with consumers – you can read our reflections about this in the briefing document *“Impact of and Factors Supporting Collaboration and Participatory Design”*.

Inclusive research also requires close attention to the experience and access needs of participants. In this document, we share what we have learned about making research tools and materials user-friendly and inclusive. You are welcome to adapt these ideas for your own work.

What is “usability” and how does it relate to research?

Do you remember the last bad survey you took? Perhaps it took longer than advertised or was too complicated. Were the questions confusing, or badly structured? Did the topics or terminology lack relevance to your own life? If so, Figure 7 may be relatable!

Figure 7: Examples of long and confusing survey questions.



The term “usability” refers to how easy something is to use. Usability is important for successful services, products, and environments. Common principles associated with good user experiences include:

- Usefulness:** Meeting an existing need
- Consistency:** The user experience is predictable and familiar
- Simplicity:** Being simple and intuitive to use
- Efficiency:** Minimises effort and time-costs
- Clarity:** Offering clear information and instructions
- Durability:** Preventing and resolving any errors in use
- Accessibility:** Accommodating diverse user needs

Usability principles hold just as much significance for the design of **research experiences** as they do for other products and services.

Why is usability important to research?

If your research processes or materials have poor usability, research participants are more likely to leave your study. This limits the quality and quantity of your data, and the strength of your research findings. Frustration with research tools or activities can also harm the relationship that participants have with the academics or services that are conducting the research. Good usability creates better experiences for all research participants, but is especially important for some populations including: People with busy schedules, such as parents, carers, or busy professionals; people with disability or health conditions; people with language differences or low literacy, and people who are experiencing personal or situational stress. These groups represent a significant portion of the general population and are important voices to include in research. To capture these perspectives, good usability of research tools and processes is essential.

Good usability creates better experiences for all research participants, but is especially important for some populations including:

- *People with busy schedules, such as parents, carers, or busy professionals,*
- *People with disability or health conditions,*
- *People with language differences or low literacy, and*
- *People who are experiencing personal or situational stress.*

Improving usability through co-design

Put simply, co-design involves “making things and learning what works” and requires “working with the people who are closest to the solutions” (McKercher, 2021). In the case of research, this means working with people who are similar to your target research participants (e.g., community members, service users, or professionals).

In our project, the university researchers worked closely with the My Active Life National Project Managers and Lived Experience Advisory Group (LEAG), to co-design our research questions, tools, and activities. The LEAG included six people with disabilities and supporters / carers of people with disability, who were involved or invested in inclusive recreation. Working with this team improved the overall usability of our research.

We undertook several steps as part of the co-design process:

- The university researchers read and summarised published articles and guidelines about inclusive research design and research participant experiences.
- The LEAG members critiqued existing research tools (e.g., Quality of Life questionnaires, consent forms), and provided feedback.
- The whole research team co-designed new research tools (e.g., recreation and health resource use measures; satisfaction measures, and dynamic consent processes).
- LEAG members tested and provided feedback on each tool, using a “Think Aloud” user-testing method. You can learn more about this method [here](#).
- We used accessibility testing tools such as [Accessibility Checker](#) to ensure our tools met international accessibility standards such as the [Web Content Accessibility Guidelines](#) (WCAG 2.1).



Finding a compromise

Sometimes we had to find a compromise between usability and other priorities, such as research sensitivity, accuracy, or cost. For example, we noticed that some standardised tools (e.g., for measuring Quality of Life) had poor usability, but changing these was not easy. Standardised tools have been tested with large groups of people to enable researchers to compare results from a group of participants to a general population. Changing the tools makes the comparisons less accurate. We talked about the benefits and drawbacks of making changes, and decided which changes were the most important for these tools. Some suggested usability measures (such as translating tools into multiple languages or having someone to assist participants in completing surveys over the phone) were too expensive or resource intensive for the current project. Explaining the nature of standardised research methods to the LEAG participants and having transparency about project resources helped us to make informed and balanced decisions as a team.

What we learnt

We have gained several insights about usability and inclusion through our work in this project. The following guide outlines nine principles that we have identified for inclusive research, and the ways these can be achieved.

Principles of Inclusive Research

1. Usefulness
2. Flexibility
3. Choice and Control
4. Consistency
5. Efficiency
6. Clear Communication
7. Accessibility
8. Respect
9. Resilience

Principles of Inclusive Research

1. Usefulness

Research questions and outcomes should always have value to the populations at the centre of the research. This means **only undertaking research that is necessary and important**.

Here are six things you can do to improve the usefulness of your own research:

1. Conduct a **comprehensive literature review** to identify what topics have already been studied enough, and how your research can update or fill gaps in existing knowledge.
2. Talk to members of the community that you are researching, to identify their **priorities and needs for information**. Does your research match these aims? If not, why not?
3. **Explain why you are collecting sensitive information** (e.g., financial data; questions about gender, age, or culture), or information that will be arduous for participants to report (e.g., recalling detailed information about activities or resources). Avoid asking these questions if the information will not be useful or informative.
4. **Explain how the research findings will be shared and applied**. For example, how do you expect your research to impact services or products in the future?
5. Ensure you **share your research findings via accessible formats and channels**. For example, in our project we have made plans to share our findings through mainstream media, social media, and with local politicians. Other examples of accessible knowledge sharing could include practice resources, checklists, pamphlets, posters, and advocacy guides.
6. Consider the **individual value to participants** of engaging in the research and communicate these honestly. Look for opportunities to increase this value, for instance by building in opportunities for participants to grow their networks, access resources, or build and document their skills. Where individual value is low, consider if reimbursements are appropriate, and what form these should take. For example, we have learned that in some communities it is culturally inappropriate to provide gift vouchers in lieu of money, due to the way that finances have been historically controlled for those groups. In other instances, gift vouchers may offer the most flexible and accessible solution. Conversations with diverse community members and advocates can guide these decisions.

2. Flexibility

No research method is the perfect fit for all participants. When working with diverse communities, we have found it valuable to **provide people with a choice in how they want to participate**. For example:

- Choosing to participate individually or in a group
- Choosing how people would like to communicate their perspectives, for example through spoken or Auslan (signed) interactions, written submissions, creating photographs or drawings, or using augmentative and alternative communication (AAC) tools.
- Choosing if they want to participate in further or continued research.

An online interface that we have used for this process can be viewed in more detail in a [blog post from Research Assistant Dion Williams.](#)

3. Choice and Control

It is important that research participants understand the study before they agree to participate. This is called giving *informed consent*. In traditional research, participants are given a written *Plain Language Statement* (containing information about what the study will involve) and will be required to sign a consent form. This approach can be problematic for several reasons:

- **Accessibility:** Printed consent forms can be difficult for people with vision impairment to read and sign.
- **Convenience:** Signing a consent form as a printed or electronic document often involves several time-consuming steps (e.g., printing, signing, scanning, uploading or posting/emailing a document)
- **Clarity and language:** When we have tested standard information and consent forms with some research participants, they have told us that not all of the information is important to them. Participants may skim or ignore lengthy research documents and can easily miss the information that's most important. Complex language can also make the forms harder to understand.

There are several ways that you can adapt your consent process for participants. For example, you can:






1. Use **simple language combined with meaningful pictures**, as shown in the screenshot below (figure 8a). This format is easier for people with lower literacy or language skills to understand. It can also be useful when a participant and a researcher/supporter are having a less formal conversation about the study.
2. Provide a **participant information video** (see figure 8b). We usually record our videos using Microsoft PowerPoint. They are a combination of simple spoken language, simple text, and pictures. You can also add captions or sign language, depending on the audience. Consider including a lived-experience partner in the videos if relevant.
3. Provide a **supported decision-making option** for young children and people with significant cognitive impairment, instead of proxy consent. Supported decision making is defined as an interdependent and continuous process shared between the participant and supporters who know them well (Watson, 2016). Young research participants and those with significant cognitive disability can express their preferences and feelings about the research through a range of means including facial expression, body language, gesture, physiological reactions, and behaviour. Familiar supporters can then acknowledge, interpret, and act on these expressions (e.g., by helping the person to engage in the research, or by recommending changes or discontinuation).



To learn more about these accessible approaches to consent and how we have used them in our own practice, please see this blog post: <https://blogs.deakin.edu.au/inclusivehealth/doing-inclusive-research/>

Figure 8a and 8b: Accessible online consent form with supporting pictures and video.

How do I get involved?


You can choose to:



-  Have a 1-hour interview on a video call
-  Have a 1-hour interview over the phone
-  Write your answers to interview questions and send them in an email
-  Draw 3-5 pictures and talk about them with someone from the research team
-  Take 3-5 photos and talk about them with someone from the research team

You have chosen that you would like to **support someone to take 3 - 5 photos and talk about them with someone from the research team.**

If you like, you can watch the video below which has Closed Captions. It will let you know all the information in the consent forms about **taking photos** for this research. It also lets you know about the information in your photo manual. This manual includes important information about what types of photos can be included in this study and some rules to follow when taking your photos. [Please click here to download and save a copy of the photo manual for your use.](#)



Watch on  

4. Consistency

The research experience should be **consistent, familiar, and predictable**. You can achieve this by:

1. Ensuring that any documents or surveys in your study **look and operate the same way**. This means that returning participants will know what to expect.
2. Follow a **consistent and predictable structure** in your surveys and documentation – e.g., keep your headings, formatting, instructions, and controls (e.g., survey buttons and labels) consistent across different research activities. Group related information or questions, and use clear section breaks when transitioning between different concepts or topics.
3. Organise surveys and interviews in a **logical order**. For example, if you want to know about a service experience, ask questions that follow the timeline of a person’s engagement, such as finding/waiting for the service → intake process → initial appointment → receiving the service → leaving the service. This helps to make recall easier and more efficient.
4. Use **appropriate language and terminology** for the community you are researching. For example, describe health conditions, services, and procedures using the language your participants will be most familiar and comfortable with. You can learn about these terms by reading public documents from relevant services, by observing services in action, or by asking community members such as a LEAG.
5. Provide **practical examples** to help people recognise a familiar concept – for instance:
 - “Do you use a mobility aid (e.g., a walking stick, wheelchair, scooter, frame or walker) to move around?”
 - “Have you used a digital health resource (e.g., a health website, mobile health app, or wearable health sensor) during the last month?”



5. Efficiency

Participants' time is precious. To ensure maximal efficiency and reduce workload for participants, consider the following strategies:

1. **Only show important information.** Reduce clutter and eliminate any unnecessary or irrelevant elements, such as lengthy background text.
2. Allow participants to **seek additional information** if they are interested. Some participants need lots of information about a study, and others want very little. In an online survey or document, pop-up boxes or links can be used to define terms or explain concepts that some participants will know, and others won't. For in-person activities, improve efficiency by provide essential information about the study and asking if participants want to know more.
3. Use a **screening survey before an interview** to improve efficiency and make the interview questions for each participant personalised and relevant.
4. **Build in short-cuts** to make survey completion faster. For example:
 - Provide drop-down or multiple-choice options for common responses.
 - Use text prediction to auto-populate fields such as addresses.
 - Allow participants to duplicate or save data that they would need to enter multiple times (e.g., to record repeated activities, or the same data for multiple family members).
 - Allow participants to skip questions or activities that are not relevant or important to them, unless these are essential to your research.
 - Allow participants to provide a range or an estimate for numeric data (e.g., activity frequency, travel time, income, cost, etc.), instead of asking them to recall an exact number.

6. Clear Communication

Technical words or complex language can be confusing for research participants. Written documentation can also be a barrier for people with limited English proficiency, or those with low literacy skills. Approximately 40% of Australians have literacy abilities below the level needed to participate comfortably in work, education, and society.

To improve the clarity of your research documents and activities, you can:

1. Provide **clear and simple instructions** at each point of engagement. For example, include relevant instructions at the start of each survey section, rather than including them all in the survey introduction.
2. Include **visual prompts** if required. For example, we have found it helpful to include pictures to represent the specific topics or technologies that we want to know about. We also found it useful to include visual images on scales or yes/no questions (i.e., a tick and a cross).
3. Offer a **“read aloud” (text-to-speech) or recorded version of written text** where possible.
4. Where possible and relevant, **translate project materials** into additional languages that are common in the community you are researching, and allow participants to engage in the language that is most comfortable for them.
5. Regularly **remind participants of the task requirements**. For example, if you are asking questions about a specific recall period (e.g., “in the past 7 days...”), include this in every question.
6. Provide **clear and quick feedback to participants**, so they know what is going on. For example:
 - Include progress indicator bars or section numbering on surveys, so participants can plan their time and monitor the workload of the survey.
 - Confirm that you have received project documentation (e.g., consent forms, survey responses).
 - Provide an option for participants to view or save their own contributions, and to receive a summary of the project findings. This allows them to see the impact of their input.

7. Accessibility

There are many considerations for accessibility in research. Some of the most important principles are as follows:

- Ensure adequate visual accessibility: this includes using an appropriate font size, colour contrast and background. For more information, see Vision Australia’s blog post on [inclusive design and legibility](#).
- Ensure that electronic resources be read and accessed using a screen reader (software that reads screen contents aloud) for those who cannot see or read. For more information, see this online lesson from W3 Schools: [Accessibility Screen Readers](#).
- Ensure that electronic resources can be navigated through and accessed using an alternative to a standard keyboard or mouse. For example, you may need to provide an alternative to on-screen signatures for those who cannot use a finger or stylus to sign.
- Enable any “read-aloud” features that are provided by the system.
- Integrate meaningful pictures or symbols where this can support understanding.

8. Respect

It is important that all users feel respected as they engage with your research materials. To ensure that your content is respectful and inclusive, consider the following:

1. **Use health or disability terminology that is preferred** by the community you are studying. For example, should you use the term “diabetic” or “person with diabetes?” Should you use the term “neurodiverse”, “Autistic”, or “person with Autism?”. Sometimes you may need to provide multiple terms to ensure everyone feels included and respected.
2. **Avoid making assumptions** about participants’ lived experience. For example, phrases like: “do you suffer from [health condition]...” or “are you dependent on [equipment]...” imply that all people will have a negative experience of their disability or health condition. Neutral terms like “do you experience...” or “do you use...” are more empowering and accommodate a wider range of perspectives and experiences.
3. If you need to ask about a person’s gender identity, **provide a range of inclusive gender options** such as “non-binary”, “other”, and “prefer not to say”. Provide room for participants to describe their preferred terminology if it’s not listed.
4. Consider the **implications of requesting and reporting on cultural heritage**, such as a participant’s identification as Aboriginal or Torres Strait Islander. These questions can be sensitive, so consult with relevant community members before you ask.
5. Consider the **impact of visual imagery**. For example, are the pictures used age appropriate, culturally appropriate, and relevant to participants? Do they represent the diversity of your participant groups?

For more information and guidance, we recommend consulting your community advisors and following the guidance of the Australian Government Style Manual: <https://www.stylemanual.gov.au/accessible-and-inclusive-content/inclusive-language>



9. Resilience

No matter how careful your design is, research participants will still make mistakes in their use of research tools. They may also interpret instructions or provide input in unexpected ways. Your research process needs to be able to accommodate these errors and variations, to ensure that participant data can still be used accurately.

Some of the ways you can improve the resilience of your research tools and processes include:

1. **Undertake testing** (trial-runs) of research activities, documents and tools with people who match your target participant group. This will help you to identify common errors, points of confusion and possible alternative responses ahead of time.
2. **Warning participants when an action will result in a major consequence.** For example, warning them that selecting a response or clicking a button will end a survey or remove them from the research.
3. Giving participants an **option to remove, undo, or correct a response** after they have provided it. This will help to reduce participants' anxiety around making errors.
4. Creating an easy process for participants to return to a survey or research activity if they get interrupted or need to take a break.
5. Using **text validation to detect typographic errors** in important information – for example, if a numeric answer contains letters, if a date is outside of the expected range, or if an email or phone number appears incomplete. If you are using validation, please ensure that the checks accommodate the full range of valid entry options (e.g., phone numbers with and without country codes), to reduce participant frustration.
6. Where possible, **provide a clear explanation when something has gone wrong, and clear instructions on how to fix it.**

Summary

Just because a research tool or approach has been used for decades, this does not mean it is the best tool for every project. With co-design and better attention to usability we can humanise the research process, empowering participants to share their valuable perspectives without draining their energy or dignity in the process.

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This report was developed as part of a commissioned project investigating inclusive sport and recreation in the TAD Australia Network 'My Active Life' program. If you would like more information about this project, please email assistivetech@deakin.edu.au.

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Project Technical Report



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Project Technical Report

Introduction

This section of the report outlines in more detail the steps taken to complete this research project. Information is presented on each of the data collection methods employed and project outputs generated.

Literature Review

A review of empirical evidence relating to the engagement of people with disabilities in sport and recreation was conducted and used to inform the design of each data collection method and the interpretation of findings gained. The topics covered were as follows:

- What factors influence people's access to and use of assistive technology in sport and recreation?
- How does assistive technology influence people's participation in sport and recreation?
- What outcomes are gained from custom assistive technology?
- What are the facilitators and barriers to inclusion of people with disabilities in sport and recreation?

Project Outputs

Findings gained from the literature review are reported in the briefing documents of this report as they relate to project findings.

Interviews with Freedom Wheels Bicycle Users

As an inclusive means of gaining insight into the perceptions and experiences of Freedom Wheels users and their supporters the researchers offered a selection of ways in which people could take part in an interview. These included bringing photos or drawings along to discuss, providing a written response, or participating in an online interview with the researchers. Such flexible options were designed to invite participation of all Freedom Wheels users including children, people with intellectual disability, English literacy difficulty or digital accessibility restrictions. The aims of this method of data collection were to:

- Explore the impact that assistive technology has on people's participation in recreation and leisure activities;
- Explore user satisfaction with assistive technology devices and services; and
- Explore the factors that influence people's use of their assistive technology for recreation and leisure activities.

Ethical approval to conduct this study was gained in September 2021 (Project ID: 2021-188) and recruitment commenced mid-October 2021. Post approval, permission was gained from the ethics committee for the following amendments:

- October 2021: To enhance accessibility of recruitment and consent processes, closed-captioned videos, Plain English versions of Plain Language Statements and e-consent forms were added.
- May 2022: Stephanie Sorraghan (Deakin Occupational Therapy Honours Student) was added to the research team to enable her to collect data for her Honours research project titled: *"Inclusion in sport and recreation: Perceptions of people with disabilities and their supporters"*.
- November 2022: To address low participation rates, a modification was made that permitted the study to be promoted via external professional networks and social media and to provide participants with a \$50 incentive voucher.



Project Outputs

- Briefing document outlining findings gained.
- Case vignettes developed to showcase individual and/or community impact.
- Draft academic manuscript
- Summary of Stephanie Sorraghan's Honours Thesis titled *"Inclusion in sport and recreation: Perceptions of people with disabilities and their supporters"* (See Appendix 1)
- Electronic Poster (ePoster) Spotlight for the Occupational Therapy Australia 30th National Conference and Exhibition 2023 *"Bikes for all: How customised bicycles impact participation in sport and recreation"*
- Extended Oral Presentation for the Occupational Therapy Australia 30th National Conference and Exhibition 2023 *"Inclusion in sport and recreation: Perceptions of people with disability, and supporters"*



Online Survey with Users

The research team developed an online survey to be completed by MAL service users, to profile their needs and experiences. This survey was co-designed with the MAL National Project Managers and the LEAG to not only collect information relating to the research aims, but also to be as efficient and accessible as possible. Developing optimally accessible research tools is an important risk-management consideration, as it ensures that the inclusive reputation of participating organisations is upheld and reduces risk of research attrition due to poor participant experience. In line with a participatory research approach, an iterative co-design process was employed, and input was received from MAL National Project Managers, MAL Steering Committee, LEAG Members and Dr Jerry Lai (Analyst, Deakin eResearch) during the survey design phase.

The research team worked to ensure the data collection tools were maximally accessible and relevant to research participants, while maintaining the methodological integrity of the tools. Extensive user testing was completed and, in response to feedback received, changes were made to three key areas: language (e.g., triggering words, consistency across questions, use of Plain English); content presentation (e.g., were questions logically presented? Do questions follow what is seen in similar surveys?); and streamlining Resource Use Measures (RUMs). Examples of changes made to the RUMs included: adding predictive text for entry of addresses; adding a feature to save names of supporter details for use in subsequent RUMs; and creating repeated events that allow respondents to make copies of activities they engage in repeatedly eliminating the need to complete multiple identical forms (for example, going to basketball at the same venue with Mum and Dad 3 times a month). The learnings gained from this experience were recorded and used to inform development of Inclusive Research Guidelines.



In June 2021, ethics approval was granted (Project ID: HEAG-H 59_2021) and the online survey was launched for data collection in September 2021. To address low rates of response, two modifications were made to the original ethics approval:

- September 2021: As recognition of people's time taken to complete this survey, ethics approval was gained to offer a \$100 gift voucher randomly drawn at the start of each month;
- February 2022: Changes were made to the recruitment method being used by staff of the TAD Australia Network; survey questions were modified to reduce the length of time taken to complete the survey; and in response to feedback from the MAL Steering Committee, the research team added a question to elicit participant feedback on Inclusive Community Sports Days.

Project Outputs

- Briefing document reporting on findings gained
- Guidelines on Inclusive Research
- Draft academic manuscript



Interviews with Service Providers

Interviews were conducted with a range of community-based sport and recreation service providers to evaluate the impact of MAL services that aim to enhance the capacity of providers to deliver inclusive services for people with disabilities. More specifically this project addressed the following questions:

- How do service providers perceive the impact of having MAL services support their agency to offer more inclusive sport and/or recreational services or events?
- How do service providers perceive the concept of 'inclusion' in relation to sport and recreation?
- What do community service providers perceive as barriers and facilitators to delivering inclusive sport / recreational services or events?

Ethical approval to conduct this study was gained in June 2022 (HEAG-H 53_2022) and interviews were conducted 2022-2023.

Project Outputs

- Briefing document reporting on findings gained
- Draft academic manuscript



Participatory Action Research

The Deakin researchers have worked in partnership with the LEAG throughout the duration of this project. Collaborations have included the co-design of data collection tools, co-analysis of data collected, co-creation of knowledge translation plans and generation of project outputs such as conference papers and journal manuscripts.

To formally reflect and analyse on the process by which the LEAG has worked with Deakin researchers and to evaluate outcomes gained, a research protocol was established and ethics approval for this study was gained August 2022 (modification to Project ID: HEAG-H 188 2021). The aim of this study was to explore experiences of LEAG members who worked as collaborators on this project.

Project Outputs

- Briefing document reporting on findings gained.
- Draft academic manuscript
- Extended Oral Presentation for the Occupational Therapy Australia 30th National Conference and Exhibition 2023 Presentation titled *“Learning together: Reflections on co-designing research with a Lived Experience Advisory Group”*.
- In recognition of its collaborative work and achievements, the LEAG was acknowledged as a Finalist in the 2022 National Awards for Disability Leadership.

Project Constraints

Disappointingly, the recruitment rates for this project have been substantially lower than anticipated, despite the project design and data collection tools being co-designed with the MAL National Project Managers and the LEAG. Throughout the entirety of the project, the Deakin researchers have worked closely with the MAL National Project Managers to identify and remedy potential recruitment barriers. Several strategies were employed by both parties but unfortunately recruitment rates remained low. Although the reasons cannot be fully understood it is plausible that the following factors were influential:

- The MAL program was overseen nationally and delivered by state-based organisations. The large number of staff involved in the delivery of MAL services may have potentially impacted the adherence to recruitment processes across state parties in the MAL consortium. Strategies implemented to address this risk included: attendance at MAL state staff meetings by the Deakin research team; development of a video for distribution to Freedom Wheels clinicians; regular reporting on response rates; and development of study promotion materials for use at Freedom Wheels events.
- Once receiving their custom AT and being satisfied with their device, people may have been less inclined to respond to communication from the TAD Australia Network.
- Covid-19 and related restrictions slowed the delivery of MAL services, particularly in NSW & Victoria. It is possible that this influenced the numbers of participants in the early stages of this project.



Appendices

Appendix 1: Summary of 2022 Occupational Therapy Honours Project by Stephanie Sorraghan

Inclusion in sport and recreation: Perceptions of people with disabilities and their supporters.

Inclusion can be considered as a state of being, or as something that can be practiced (Hocking, 2019). The ability to practice inclusion highlights the ability of individuals to behave in ways that enhance feelings of inclusion for others, such as people with disability. When individuals do not feel included in their meaningful occupations, their wellbeing and sense of self can be negatively affected (Hocking, 2019). Sport and recreation are meaningful occupations to many individuals, with 13 million adults estimated to participate in sport per year in Australia (Australian Government Department of Health, 2022). However, data indicates that 72% of adults living with disability did not get enough physical activity in 2017-2018 (Australian Government Australian Institute of Health and Welfare, 2022), despite data suggesting people with disability have a desire to be involved in sport and recreation (VicSport, 2022). Additionally, although occupational therapists commonly work with individuals with disability to support them in engaging in their meaningful activities (Occupational Therapy Australia, 2019), interventions targeting leisure occupations, such as sport and recreation, are often not prioritised over those addressing self-care and productivity occupations (Chen & Chippendale, 2018).

What we did

This study took an interpretive phenomenological approach to answer the research question: 'How is inclusion in sport and recreation perceived by people with lived experience of disability?' The study aimed to explore the experience of engaging in sport and recreation for people with lived experience of disability, and the factors influencing their inclusion. This aim was broken into the following objectives:

1. explore what 'inclusion' means to people with lived experience of disability;
2. analyse the factors that act as enablers and barriers to inclusion in sport and recreation for people with disabilities.

Semi-structured interviews were used to explore inclusion from the perspective of people with lived experience of disability who are involved in sport and recreation. Six participants took part in the study, and data were analysed using interpretive phenomenological analysis, an approach used widely throughout health research which supports researchers in analysing intricate topics focussed on the

experiences of participants (Peat et al., 2019). Findings were presented as four themes, and the Model of Human Occupation (Taylor & Kielhofner, 2017) was used as an underpinning framework during the discussion of results to highlight links between the research topic and occupational therapy practice.

What we learnt

Findings suggest that people with lived experience of disability perceive inclusion within sport and recreation as meaning more than physical participation, and that being included enables one to experience outcomes associated with, yet beyond, participation in sport and recreation. Several factors were reported to act as enablers and barriers to inclusion within sport and recreation for people with disability. These included environmental accessibility, the use of assistive technology, the influence of parents, peers, and coaches, and the actual 'doing' of sport and recreation itself. Findings were discussed in relation to existing literature, and the factors acting as enablers and barriers were linked to components of the Model of Human Occupation (Taylor & Kielhofner, 2017), to highlight how occupational therapy intervention may enhance inclusion. Occupational therapists commonly provide intervention at individual, environmental, and occupational levels (McColl & Law, 2013), and may utilise this study's findings as evidence in future intervention planning. Additionally, as sport and recreation are important leisure occupations for many individuals (Costalonga et al., 2020), these findings may support occupational therapists in prioritising leisure occupations when working with individuals living with disability into the future. By working to enhance feelings of inclusion within sport and recreation for people with disability, individuals may be enabled to participate meaningfully and experience the variety of physical and mental health benefits associated with living an active lifestyle.

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Appendix 2: My Active Life Project Findings - Political and Media Talking Points

We have collated four key messages arising from this research that we think may be of interest to politicians, the media, or the general public. They could be used as a starting point for press releases, offered as topics for interviews or news articles, or brought into consultation sessions with a local council member or Member for Parliament. They may also provide useful context to social commentary, reporting or policy development for issues such as inclusive sports or accessibility in urban planning.

Insight 1: Access to recreation and assistive technology is a protected human right.

Access to recreation is a legally protected right in Australia under the Disability Discrimination Act (DDA). Access to assistive technology for mobility, including adapted bikes, is also protected under this act. For more information see: [DDA – Sport and Recreation](#) and [HumanRights.gov – Accessible Technology](#).

Insight 2: Adapted cycling is an important means of recreational and social inclusion.

Adaptive bikes offer a range of benefits for people with disability and their families (see report pages 15-17), including:

- Participation in recreation, leisure or competitive sport with community, family members or friends.
- Increased range and independence in outdoor mobility.
- Increased physical fitness, confidence, and social capital.

Insight 3: Access is key.

While adapted bikes can support inclusion, they can be difficult to transport and use in public spaces (see report p. 22). A standard adapted bike is 800mm wide and 850mm tall. Narrow footpaths, parked cars, unattended e-scooters, and pavement furniture such as café chairs and tables can make it difficult or even dangerous to ride an adapted bike. Additionally, access to recreation requires attention to systemic factors including the affordability of recreation activities, the accessibility of locations and transport, and the impacts of inclusive versus exclusionary attitudes and practice (see report p. 80-81).

Insight 4: Accessible bike programs require appropriate funding to meet demand.

Many rides of adapted bikes have complex disability and require a solution that is individually tailored to their needs (see report pages 20-21). With improved recreational goal setting under the NDIS, custom cycling solutions are in high demand. However, there are significant labour and resourcing costs involved in fitting, prescribing, making, and trialling a custom adapted bike, and increasing community awareness of adapted cycling options. Much of this work is non-billable under the NDIS, and custom bike providers like the TAD Australia Network are currently reliant on a volunteer workforce to meet demand. Increased funding and tailored funding models will be needed to ensure the growing community of adaptive riders can access affordable support and equipment into the future.

Practice Recommendations

Practice recommendations for **Governments, local councils and urban planners** include:

- Consider options for secure parking and transportation of adapted bikes in addition to wheelchairs and mobility scooters. This includes considerations for the width and height of storage bays, as adapted bikes are larger and heavier, and cyclists with disability may have more difficulty in manoeuvring or lifting their bike.
- Creating maps of accessible and inclusive cycling routes.
- Ensure that all new or updated cycling facilities consider accessibility and safety for all users, including pedestrians with and without disability, people using mobility aids, and those using adapted cycling equipment.
- Encourage the inclusion of non-standard cycles in bike rental and bike-share schemes.
- Understand the complex costs of operating the custom assistive technology services that provide adapted bikes, and work in partnership with these organisations to ensure sustainable funding and infrastructure supports remain available.

Practice suggestions for **community members** include:

- Educate local businesses (e.g., cafes, restaurants) about the minimum width that pavements should be kept clear to accommodate wheelchairs, mobility scooters, and adapted bikes.
- Maintain the pavement space outside of your business or home, and report hazards (e.g., cracked pavements, overgrown hedges/nature strips, and abandoned items) to your local council.
- Contribute to inclusive recreation spaces by being mindful of cyclists with disability when you are using the road or cycle paths.

Recommended Resources

Some external resources for accessibility in cycling and urban design include:

- [C40: How to grow cycling by improving equity and accessibility](#).
- [Wheels for Wellbeing: A guide to inclusive cycling](#) (Opens as a pdf).
- [United Nations: Good Practices in Accessible Urban Development](#) (Opens as a pdf)
- [Henderson-Wilson, Andrews, Wilson & Tucker \(2022\): Global Benchmarking of Accessible and Inclusive Cities](#) (Opens as a pdf).

Appendix 3: Survey Tools

Rum Recreation Activities (User)

Resource Use Diary: Recreation Activities

This survey is about your use of Recreation Services, which are organisations, businesses or facilities that support your recreational activities. Recreation services can be paid or free.

We are interested in how you have used recreation services in the past 2 weeks. We will use this information to understand how the time and money you spend on these recreation services changes as the study goes on.

You do not need to tell us about:

- Therapeutic recreation activities that you complete with supervision or guidance of a registered health professional (e.g. clinical pilates, hydrotherapy, exercise physiology). We will ask about these later in the survey.
- Informal leisure or recreation activities that you engaged in e.g. walking around your neighbourhood, going shopping, or activities at home or another private residence.

If you do not want to do this section of the survey you can skip it by clicking the submit button at the bottom of this page.

The following questions relate to a single recreation and leisure event or activity that you completed in the past month.

Which of the following categories best describes the service(s) used for this activity?

- Organised play, sports or physical activities (e.g., community sports, gaming communities/competitions, crafting group, walking group).
- Recreation skill-building (e.g., personal training, dance class, yoga class).
- Access to specialised recreation or leisure facilities (e.g., adventure park, gym, swimming pool, tennis court). Publicly accessible leisure facilities (e.g., playground, cycling track, bush-walking trails).

The first questions are about the activity's purpose.

What specific activities did you do while using the service?

What was the purpose/goal of this activity (e.g., fun, fitness)?

How long were the recreation or leisure services used for?

- Less than 30 minutes
- 30 minutes – 2 hours
- 3 hours – 4 hours
- 5 hours – 8 hours
- More than 8 hours

The following questions will allow us to calculate the time cost of participating in this recreation activity.

Person/people involved in this recreation or leisure activity:

- Myself
- [supporter_01]
- [supporter_02]
- [supporter_03]
- [supporter_04]
- [supporter_05]
- paid carers / support workers
- Other unpaid supporters (e.g., family and friends)

Did everyone travel together?

- Everyone travelled together
- Some people travelled separately

Please tick box before entering any unpaid or compensated time

Please indicate how much time you spent on this activity:

- I spent _____ minutes of my own time on this activity.
- I spent _____ compensated minutes on this activity (e.g., paid leave or reimbursed time).
- Don't know / prefer not to say how much time I spent.

How much time did [supporter_01] spend on this activity? (indicate as many as relevant):

- _____ minutes of their own (unpaid) time.
- _____ minutes of compensated time (e.g., paid leave).
- Don't know / prefer not to say

How much time did [supporter_02] spend on this activity? (indicate as many as relevant):

- _____ minutes of their own (unpaid) time.
- _____ minutes of compensated time (e.g., paid leave).
- Don't know / prefer not to say

How much time did [supporter_03] spend on this activity? (indicate as many as relevant):

- _____ minutes of their own (unpaid) time.
- _____ minutes of compensated time (e.g., paid leave).
- Don't know / prefer not to say

How much time did [supporter_04] spend on this activity? (indicate as many as relevant):

- _____ minutes of their own (unpaid) time.
- _____ minutes of compensated time (e.g., paid leave).
- Don't know / prefer not to say

How much time did [supporter_05] spend on this activity? (indicate as many as relevant):

- _____ minutes of their own (unpaid) time.
- _____ minutes of compensated time (e.g., paid leave).
- Don't know / prefer not to say

The next questions are about the travel arrangements of each group (travel party) attending the activity.

First/Main Travel Party

From (Starting Location): Suburb

Address / Organisation (If known):

To (Activity Location): Suburb

Address / organisation (If known)

Travel Mode: How did this person/group travel to the activity?:

Second Travel Party (if relevant)

From (Starting Location): Suburb

Address / Organisation (If known):

To (Activity Location): Suburb

Address / organisation (If known)

Travel Mode: How did this person/group travel to the activity?:

Third Travel Party (if relevant)

From (Starting Location): Suburb

Address / Organisation (If known):

To (Activity Location): Suburb

Address / organisation (If known)

Travel Mode: How did this person/group travel to the activity?:

How was this appointment paid for?

- Included in a service package
 - Private Health Insurance
 - TAC
 - WorkCover
 - NDIS
 - Aged Care Package
 - Self-funded/co-pay _____
 - Other: _____
-

Did the person you support do this activity more than once in the past 2 weeks? (i.e., the same activity and location, with the same people and travel arrangements).

- Yes
 - No
-

How many times did the person you support do this exact activity in the past month?

(Please enter a number)

We have now saved these details. You won't need to enter instances of this activity again in this month's survey.

If the information that you have provided about the last two weeks of recreation costs is unusual and you would like to tell us the reason you can do so here.

Comments:

To log another recreation activity, please select "add a new form".

If you are ready to proceed to the next survey section, please select "submit".

Add a new form

SUBMIT

Rum Recreation Activities (Proxy)

Resource Use Diary: Recreation Activities

This part of the survey is about how the person you support uses Recreation Services, which are organisations, businesses or facilities that support these activities. Recreation services can be paid or free.

We are interested in how the person you support has used recreation services in the past 2 weeks. The researchers will use this information to understand how the time and money the person you support spends on these recreation services changes as the study goes on.

You do not need to tell us about:

Therapeutic recreation activities that the person you support complete under the supervision or guidance of a registered health professional (e.g. clinical pilates, hydrotherapy, exercise physiology). We will ask about these later in the survey.

Informal leisure or recreation activities that the person you support engaged in, such as walking around your neighbourhood, going shopping, or engaging in recreation at home or another private residence.

If multiple activities were completed, you can load new questions by clicking 'Add a New Form' at the bottom of this page.

If you do not want to do this section of the survey you can skip it by clicking the submit button at the bottom of this page.

The following questions relate to a single recreation or leisure event or activity that the person you support completed in the past 2 weeks.

The first questions are about the activity's purpose.

Which of the following categories best describes this activity?

- Organised play, sports or physical activities (e.g., community sports, gaming communities/competitions, crafting group, walking group).
 - Recreation skill-building (e.g., personal training, dance class, yoga class).
 - Access to specialised recreation or leisure facilities (e.g., adventure park, gym, swimming pool, tennis court). Publicly
 - accessible leisure facilities (e.g., playground, cycling track, bush-walking trails).
-

What was the purpose/goal of this activity?

What specific activities did the person do while using the recreation/leisure services?

How long were the recreational/leisure services used for (not including travel time)?

- Less than 30 minutes
- 30 minutes - 2 hours
- 3 hours - 4 hours
- 5 hours - 8 hours
- More than 8 hours

The following questions will allow us to calculate the time cost of participating in this recreation activity.

Person/People involved in the activity:

- Myself
- The service user I support
- [supporter_01]
- [supporter_02]
- [supporter_03]
- [supporter_04]
- [supporter_05]
- paid carers / support workers
- Other unpaid supporters (e.g., family and friends)

Did everyone travel together?

- Everyone travelled together
- Some people travelled separately

Please tick box before entering any unpaid or compensated time

How much time did you spend on this activity? (indicate as many as relevant):

- I spent _____ minutes of my own time on this activity.
- I spent _____ compensated minutes on this activity (e.g., paid leave or reimbursed time).
- Don't know/Prefer not to say how much time I spent.

How much time did the person you support spend on this activity? (indicate as many as relevant):

- The person I support spent _____ minutes of their own time on this activity.
- The person I support spent _____ compensated minutes on this activity (e.g., paid leave or reimbursed time).
- Don't know / Prefer not to say how much time the person I support spent.

How much time did [supporter_01] spend on this activity? (indicate as many as relevant):

- _____ minutes of their own time on this activity.
- _____ compensated minutes on this activity (e.g., paid leave or reimbursed time).
- Don't know / prefer not to say.

How much time did [supporter_02] spend on this activity? (indicate as many as relevant):

- _____ minutes of their own time on this activity.
- _____ compensated minutes on this activity (e.g., paid leave or reimbursed time).
- Don't know / prefer not to say.

How much time did [supporter_03] spend on this activity? (indicate as many as relevant):

- _____ minutes of their own time on this activity.
- _____ compensated minutes on this activity (e.g., paid leave or reimbursed time).
- Don't know / prefer not to say.

How much time did [supporter_04] spend on this activity? (indicate as many as relevant):

- _____ minutes of their own time on this activity.
- _____ compensated minutes on this activity (e.g., paid leave or reimbursed time).
- Don't know / prefer not to say.

How much time did [supporter_05] spend on this activity? (indicate as many as relevant):

_____ minutes of their own time on this activity.

-
- _____ compensated minutes on this activity (e.g., paid leave or reimbursed time).
 Don't know / prefer not to say.

The next questions are about the travel arrangements of each group (travel party) attending the activity.

First/Main Travel Party

From (Starting Location): Suburb

Address / Organisation (If known):

To (Activity Location): Suburb

Address / organisation (If known)

Travel Mode: How did this person/group travel to the activity?:

Second Travel Party (if relevant)

From (Starting Location): Suburb

Address / Organisation (If known):

To (Activity Location): Suburb

Address / organisation (If known)

Travel Mode: How did this person/group travel to the activity?:

Third Travel Party (if relevant)

From (Starting Location): Suburb

Address / Organisation (If known):

To (Activity Location): Suburb

Address / organisation (If known)

Travel Mode: How did this person/group travel to the activity?:

How was this appointment paid for?

- Included in a service package
 - Private Health Insurance
 - TAC
 - WorkCover
 - NDIS
 - Aged Care Package
 - Self-funded/co-pay _____
 - Other: _____
-

Did the person you support do this activity more than once in the past 2 weeks? (i.e., the same activity and location, with the same people and travel arrangements).

- Yes
 - No
-

How many times did the person you support do this exact activity in the past 2 weeks?

(Please enter a number)

We have now saved these details. You won't need to enter instances of this activity again in this month's survey.

If the information that you have provided about the last two weeks of recreation costs is unusual and you or the person you support would like to tell us the reason you can do so here.

Comments:

To log another recreation activity, please select "add a new form".

If you are ready to proceed to the next survey section, please select "submit".

Add a new form

SUBMIT