



# A Profile of Custom Assistive Technology Users

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## 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.

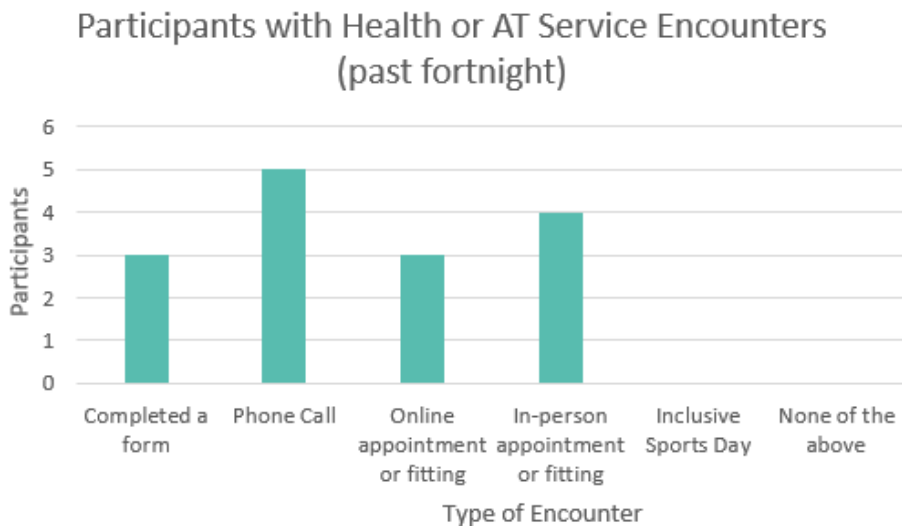
## Income and employment

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.

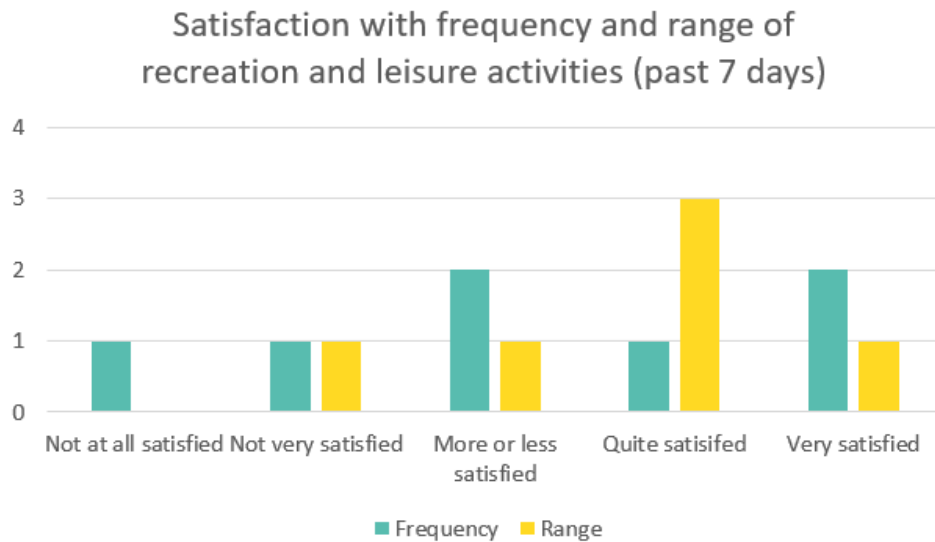
**Figure 4:** Participants with Health or Assistive Technology Service Encounters (past fortnight)



## 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)

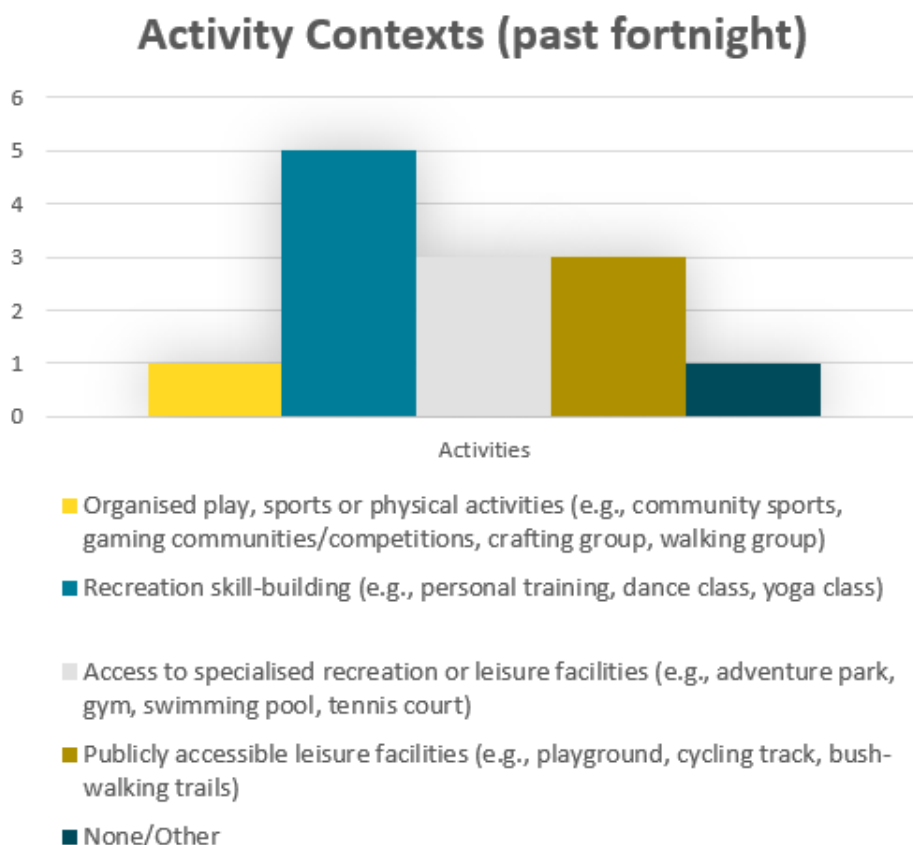


### Recreation service use

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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