



The experiences of young people with limb difference in participating in sports and recreation in an Australian context: a qualitative study.

A Melbourne Disability Institute community-based research scheme project in partnership with the START Foundation.
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1. Acknowledgements and context

We acknowledge that this study was undertaken on lands of Traditional Custodians across Australia, in particular on the lands of the Wurundjeri Woi Wurrung, Boonurong and Gunai Kurnai peoples in Victoria. We pay our respects to Elders past and present and thank them for their care and custodianship of the land, waterways and all living things for millennia. We acknowledge that this care and custodianship is ongoing and contributes to good health and wellbeing for all Australians.

This study was funded in part through a Melbourne Disability Institute Community-Based Research Program grant. The START Foundation was a charitable organisation that empowered amputees in life through sport, by providing grants to purchase sports prostheses or adaptive sports equipment, to help them achieve their sporting dreams. The START foundation applied for a Community-Based Research Program grant in 2019 and was connected to Dr Rachel Toovey. Together Michelle Jelleff, former CEO of the START foundation, formed a team of investigators, and refined the aims of the study. The aims, approach, outcomes and implications of this work are detailed in this report.

Since commencement, personal and societal events impacting the timeline of the project include:

- The Covid pandemic of 2020-23 which impacted sports participation globally, in particular in Victoria, Australia.
- The increasing accessibility of funding for sports and recreation prostheses and adaptive equipment through the National Disability Insurance Scheme, meant the role of the START Foundation in filling the funding gap diminished and it ceased operation in late 2022.
- Dr Rachel Toovey was on parental leave from November 2020 – November 2021.

We would like to acknowledge the young people and parents who participated in this study by generously sharing their experiences and stories. We would also like to thank the Melbourne Disability Institute for contributing funds and support to this project. We are grateful to all investigators for their varied and important contributions to the study most of whom provided time to this project in-kind. We would particularly like to thank Michelle Jelleff from the START foundation who envisioned this project and gave it context and meaning over the last 3.5 years.

2. Executive Summary

The primary objective of this study is to investigate the experiences of young people with limb difference in participating in sports and recreation in an Australian context. A qualitative study was undertaken with nine family dyads recruited from organisations and outpatient clinics across Australia via convenience sampling.

Young people were aged between 9-16 years, with seven having unilateral limb differences (upper limb $n=2$; lower limb $n=5$), and two with bilateral limb differences (upper limb $n=1$; lower limb $n=1$). All participating parents were mothers. Data were collected via 18 semi-structured interviews (duration between 20-59 minutes) and analysed using an interpretive description approach.

Three themes were interpreted from the data:

1. *"Just treat me like everyone else"*: equitable participation in sports and recreation,
2. Genuine choice within sports and recreation activities: *"provide them opportunities and let them take the lead"*, and
3. *"I wish they were easier to get"*: the impact of sports-specific prostheses on young people's participation.

Facilitators and barriers to participating in sports and recreation developed from the results were mapped into the socio-ecological model to illustrate the levels at which these influences operate and where possible interventions could be directed. A conceptual model was then developed synthesising the themes, responses to member checking, the broader literature, and experiences of the project team. This model was entitled *"Moving through childhood: The cycles of participation supports for young people with limb difference"*

3. Introduction & Background

Participation in sport has been described as a fundamental human right (United Nations, 2016). Children with disabilities who participate in sport have been reported to have better quality of life, self-esteem and confidence, and better fitness and gross motor skills (Murphy et al., 2008; Te Velde et al., 2018; Wind et al., 2004). The benefits of participating in physical activity more generally among children with disability are clear and well documented in the literature (Anaby et al., 2013, 2020; Law et al., 2011; Patel & Greydanus, 2010; Shields et al., 2012, 2015; Shields & Synnot, 2016). Benefits of physical activity for children include social inclusion, improving physical fitness and motor coordination, and increased self-esteem and quality of life (Ahmed et al., 2018; Batista et al., 2019). However, children with disability participate in less physical activity compared with their typically developing peers (Ahmed et al., 2018).

Limb difference (LD) is a physical disability that can be acquired congenitally through genetic causes or maternal exposure to environmental toxins (Alexander et al., 2016). Alternatively, LD may be acquired due to trauma or disease such as cancer or infection and have thus required amputation (Le & Scott-Wyard, 2015). It is estimated that approximately 2500 children and young people in Australia are living with LD (Limbs4kids, n.d.).

There are few studies investigating the participation of children with LD in physical activity, and even fewer exploring sports participation. A Dutch study revealed that while many younger children with lower limb difference do not differ in their participation compared to typically developing peers, adolescents show decreased variety and interaction in both social and skill-based participation (Michielsen et al., 2011). Ahmed et al. (2018) conducted a study in Canada that investigated the facilitators and barriers to sports participation among children with LD. Some participants in this study described that having a highly functional prosthesis was highly beneficial, while some described their prostheses as a hindrance due to weight or discomfort, for example. Another Dutch study (Bragaru et al., 2013) found that for adults with LD, prosthetic functionality and comfort were also key factors influencing sports participation. Factors facilitating adult sports participation included: prior participation in sports, younger age, good health, and strong support from family and friends. Contrastingly, poor access and dependence on public transport, trivialisation from others, poor health and poor attitudes towards physical activity were considered barriers to sports participation in this study.

While some of these themes may arise in the proposed study, no study of this kind has been conducted in the Australian setting. Thus, it is important to investigate the experiences of children with LD in the Australian context, particularly considering possible differences in sporting environments and funding schemes. For example, in Canada, sports prostheses are neither covered by insurance nor through government funding (Ahmed et al., 2018). In Australia, since the implementation of the participant-directed and goal-oriented National Disability Insurance Scheme (NDIS), participants are entitled to funding that *“advances the inclusion and participation in the community of the participant with the aim of achieving his or her individual aspirations”* (National Disability Insurance Scheme [NDIS] Act, 2013, p. 46). However, the provisions may be limited by what the NDIS determines is reasonable and necessary (NDIS, 2013). These funding models may impact young people's sports participation through societal level influences, however, there may be other levels at which young people's participation is impacted.

The primary objective of this study is to investigate the experiences of children and adolescents with LD in participating in sports and recreation in an Australian context, including the perspectives of their parents. In addition, this study sought to understand the implications of these experiences for practice, and to optimise sports participation for this population.

4. Methods

4.1. Study design

This qualitative interpretive description study used semi-structured interviews with family dyads (parent/child with LD) to explore the experiences of children and adolescents with LD in participating in sports and recreation. This study is reported in accordance with the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007), and was granted ethics approval from the Royal Children's Hospital Human Research and Ethics Committee (HREC/64855/RCHM-2020).

4.2. Participants

Participants were eligible if they met all the following criteria:

- The child was aged between 8 – 17 years,
- The child had a limb difference,
- The parent provided informed consent for themselves and their child to participate,
- Both the child and parent had basic English proficiency.

The age range of 8-17 years was chosen because a previous study (Michielsen et al., 2011) used the same range, and it has been established that 8-year-olds can provide valuable information during semi-structured interviews (Kutrovátz, 2017). Participants were ineligible if either parent or child had an intellectual impairment (IQ < 70) that affected their ability to participate in interviews. Family dyads were recruited through the START Foundation, the Royal Children's Hospital's (RCH) Prosthetics and Orthotics (P & O) Unit, via relevant social media including through Amputees New South Wales.

4.3. Consent

Families were provided with information about the study in the form of two Participant Information and Consent Forms - one aimed at the parent and older children and the other aimed at younger children. Families were provided with the opportunity to ask questions about the study, and informed consent was gained from parents via a checkbox in an online survey. If parents determined their child was old enough, the child could also indicate assent to participate via another checkbox on the survey.

4.4. Data collection

Semi-structured interviews were conducted by either Chief Investigator (CI) Toovey or Associate Investigator (AI) Coulston, who are both experienced in qualitative interviewing. Interviews were held via Zoom or phone call (participant preference) and recorded via Dictaphone and/or Zoom. To enhance the security of Zoom interviews, each participant had a unique meeting ID and the meeting was password protected. Audio recordings were locally stored on The University of Melbourne's password-protected server.

The parent and child were interviewed separately, with interview durations ranging between 20-55 minutes. The interview schedule consisted of open-ended questions to facilitate the collection of rich data exploring participants' feelings and viewpoints on the intervention. The interview guides can be viewed in Appendix A, and covered topics such as current and prior sports and recreation participation, barriers and supports to participation, and coach, peer, and family influences on participation. There were slightly different questions asked for young people who used sports-specific prostheses, versus those that did not. After the interviews, each family was provided with one \$20 gift voucher for participating in the study.

4.5. Data analysis

An interpretive description approach was chosen to analyse data so that the study could generate knowledge that was applicable and meaningful to the context in which children with LD and their families live (Thorne, 2016). Through this approach, meaning is developed using an inductive approach to the data, thus developing themes from the data rather than using a preconceived list of categories (*The SAGE Handbook of Qualitative Research in Psychology*, 2023). This approach allows for the identification of unanticipated themes, particularly important due to the lack of research in this area, especially in the Australian context. It also allowed for the development of a model for use in clinical practice and/or policy to support sports and recreation participation for young people with LD.

After six interviews (3 family dyads) were completed, audio recordings were transcribed into Microsoft Word by an external company (Rev.com). AI Coulston checked these transcriptions against the audio recordings for accuracy and edited them as required. AIs Coulston and Shuttleworth then divided the transcripts between them (three each) in a collaborative approach to analysis. They familiarized themselves with the data by listening to the interviews and repeated reading of the transcripts. After familiarization, the analysts independently identified and labelled all meaningful segments within each transcript using an inductive approach, to develop the initial codes. The analysts then met to discuss the developing codes and subthemes and to assess meaning saturation.

Defined as "*a richly textured understanding of the issues*" (Hennink et al., 2017, p. 607) reaching meaning saturation in qualitative research is one way to understand if enough participants have been recruited. This assessment identified that further interviews were needed to comprehensively answer the research question. To enable the recruitment of additional participants, recruitment strategies were altered to include the Royal Children's Hospital Orthotics and Prosthesis Unit.

Another six family dyads were recruited, and 12 interviews conducted. Transcription was again undertaken by an external company (Outscribe). In this phase, the Word documents were imported into NVivo 12 software (QSR International Pty. Ltd.) for analysis. CI Toovey and AI Coulston undertook this second phase of analysis also using a collaborative approach (six transcripts each). They familiarized themselves with the data as described above. Using the codes derived from the first six interviews, the analysts independently identified and labelled all meaningful segments within each transcript as well as remaining open to the development of new codes. The analysts then met to discuss developing themes and subthemes and assess meaning saturation. As saturation was deemed to be reached at this stage, the analysts proceeded to cross-check developing subthemes and themes and develop an overall interpretation of the data.

Once preliminary themes had been developed, they were presented to Al Villalon to comment on the extent to which the themes reflected their experience as a person with limb difference. Al Villalon provided a detailed reflection (Appendix B) describing that the themes were in alignment with her experiences. A one-page summary of the results (Appendix C) was then provided to participant dyads for a member-checking process. Participants were invited to comment on the extent to which the themes reflected their experience, through either a survey, return email, or conversation with Al Coulston. Eight family dyads participated in this member-checking process, and all felt that the themes resonated with their experiences ($n=8$ survey responses), with some minor changes to wording requested.

To conceptualise how barriers and facilitators impact sports participation for young people with LD, relevant interview data were mapped into a modified Wider Determinants of Health socio-ecological model (SEM) (Dahlgren & Whitehead, 2021). The SEM is a framework that describes four levels at which an individual's health might be impacted. These levels were modified slightly for this study to include individual, interpersonal, community and societal factors. Using the SEM as a framework on which to map the influences on sports and recreation participation described by participants in the current study allowed understanding of the range of factors as well as the interplay between them (Kilanowski, 2017). Furthermore, it provided insight into which levels should be targeted to improve participation experiences for young people with LD (Kilanowski, 2017).

As a final step, the entire research team developed a conceptual model by looking for relationships and links between the overarching themes and subthemes, and drawing on the member-checking feedback, broader literature and their own experiences as clinicians, researchers, advocates and living with LD.

4.6. Rigour

Rigour relates to the research processes utilised to ensure qualitative research is trustworthy and valid (Creswell et al., 2007; Krefting L, 1991). This study's methodological rigour has been promoted through collaboration with people with LD in the study design and data analysis, peer review of the protocol, piloting of interviews, and member-checking processes. Further strategies utilised to uphold rigour are detailed in Table 1 below.

Table 1: Strategies employed to enhance rigor (Lincoln & Guba, 1986).

CRITERIA FOR RIGOR	STRATEGIES UTILISED
CREDIBILITY	<p>Prolonged engagement: Interviews were conducted over a period of 2 years. Interviewers were familiar with all aspects of the study, and were able to establish rapport with participants as evidenced by participant engagement in member-checking process. Interviews were of sufficient length to explore the research topic. Researchers undertaking analysis spent several hours familiarizing and engaging deeply with the data set.</p> <p>Triangulation: Both parents and young people were interviewed, allowing for different perspectives on the topic. Two members of the research team analysed the data in each phase, while the wider team reviewed the data analysis process and results to confirm credibility.</p>
TRANSFERABILITY	<p>Thick description: The use of detailed demographic and context descriptions will enable readers to decide if results are applicable within their own situations or settings.</p>

DEPENDABILITY & CONFIRMABILITY	Audit trail: A detailed description of the data collection and analysis process were kept throughout the study. Confirmability was achieved through discussion of the analysis process at multiple time points throughout the analysis, and through a review of the results by all members of the research team, and the participants themselves.
REFLEXIVITY	FC & RT engaged in regular reflexive discussions during the analysis process. A reflexivity paragraph will be included in the methods section of the resulting publication, discussing possible biases as researchers as well as the researcher's relationship to participants.

5. Results

5.1. Participant characteristics

Nine Australian dyads participated in the study (Victoria ($n=8$); New South Wales ($n=1$)). All parents were mothers. Young people (female ($n=3$); male ($n=5$); gender queer ($n=1$)) were aged between 9-16 years (mean 14y1m). To maintain participant anonymity, all participants have been allocated a participant code (P=parent; C=child), identifying information has been removed from quotes, and gendered pronouns replaced. As described in Table 2, two young people had bilateral limb differences (upper limb ($n=1$); lower limb ($n=1$)) while the remaining seven had unilateral limb differences (upper limb ($n=2$); lower limb: ($n=5$)). Most of the young people had used sports-specific prostheses at some point ($n=7$). One young person (C9) had recently had an amputation and was using an 'everyday' prosthesis, with plans to apply for a sports-specific prosthesis through the NDIS. C1 had never used prostheses.

Young peoples' primary current sports and recreation activities included triathlon ($n=2$), cross country ($n=2$), athletics ($n=2$), badminton ($n=2$), swimming ($n=1$), cycling ($n=1$), netball ($n=1$), table tennis ($n=1$), basketball ($n=1$), cricket ($n=1$), soccer ($n=1$). One young person did not participate in any structured sports or recreation activities but enjoyed walking with friends. Six young people identified involvement in more than one current primary sporting activity, and all young people ($n=9$) identified secondary sports and/ or recreational activities that they participated in with friends or family.

Table 2: Participant demographics.

	LIMB DIFFERENCE	PROSTHESES/ ADAPPTIONS	FUNDING MODELS UTILISED FOR SPORTS-SPECIFIC PROSTHESES	CURRENT SPORTS PARTICIPATION	PRIOR SPORTS PARTICIPATION
C1	BUL: Present at birth	Has never used prostheses. Additional adaptations: <ul style="list-style-type: none"> • use of cuff weights for exercise 	N/A	Primary: <ul style="list-style-type: none"> • Netball (mainstream local club) • PE (school) Secondary: <ul style="list-style-type: none"> • Walking (self-directed) • Running (self-directed) 	Gymnastics (club) Yoga (class)
C2	ULL: Acquired at age 8 due to illness	Currently using: <ul style="list-style-type: none"> • Blade (Filleaur Formula Prosthesis) • SwimFin • Water leg 	Personally funded, then accepted into Government Insurance Scheme	Primary: <ul style="list-style-type: none"> • Triathlon (Inclusive Sports Training program) • Cross country (school) Secondary: <ul style="list-style-type: none"> • Kayaking (camp & with family) • Golf (with support worker) 	Soccer (not described)
C3	UUL: Present at birth	Not currently using a prosthesis. Previous use of: <ul style="list-style-type: none"> • Cricket prosthesis • Skipping rope prosthesis • Velcro - multipurpose wrist strap • 3D hand Additional adaptive equipment: <ul style="list-style-type: none"> • Brake splitter for cycling • Adapted resistance bands • Velcro wrist strap for gym work 	Public hospital funding	Primary: <ul style="list-style-type: none"> • Triathlon (club) • Swimming (club) • Cycling (club) • Cross country & swimming (school) Secondary: <ul style="list-style-type: none"> • Basketball & 4-square (school, informal) • Mountain biking (social) 	Hockey (school) Cricket (not described)
C4	UUL: Present at birth	Currently using: <ul style="list-style-type: none"> • Running specific prosthesis 	Charitable organisational funding, public hospital funding	Primary:	Netball (club)

		<ul style="list-style-type: none"> • General prosthesis with adaptable ends for a variety of uses e.g. bike riding <p>Additional adaptations:</p> <ul style="list-style-type: none"> • home exercise equipment • cycling adaptation 	& Government Insurance Scheme	<ul style="list-style-type: none"> • Athletics (mainstream club & Target Talent Program through Athletics NSW) <p>Secondary:</p> <ul style="list-style-type: none"> • Cycling (social) • Surfing (social) 	Triathlon (not described) Swimming (not described)
C5	ULL: Acquired at age 12 due to trauma	<p>Currently using:</p> <ul style="list-style-type: none"> • Running blade • Water leg <p>Additional adaptations:</p> <ul style="list-style-type: none"> • Toe strap for cycling 	Government Insurance Scheme	<p>Primary:</p> <ul style="list-style-type: none"> • Badminton (school) <p>Secondary:</p> <ul style="list-style-type: none"> • Nature hiking (self-directed) • Bike riding (self-directed) • Group fitness class (with physiotherapist) 	Self-defence (school)
C6	ULL: Acquired at age 12 due to illness	<p>Currently using:</p> <ul style="list-style-type: none"> • Running blade • Water leg 	Public hospital funding & Government Insurance Scheme	<p>Primary:</p> <ul style="list-style-type: none"> • Table tennis (school) • Badminton (school, with family & prior involvement with Ability Para-club) <p>Secondary:</p> <ul style="list-style-type: none"> • Bike & scooter riding (self-directed) • Boogie boarding (with family) 	Running (prior to amputation)
C7	BLL: Acquired at age 2 (right) and 3 (left) due to illness	<p>Currently using:</p> <ul style="list-style-type: none"> • Filleaur Formula Prosthesis 	Fund-raising activities, public hospital funding & Government Insurance Scheme	<p>Primary:</p> <ul style="list-style-type: none"> • Basketball (social) • Cricket (mainstream club) <p>Secondary:</p> <ul style="list-style-type: none"> • Swimming (self-directed) • Soccer (with family) • Paddleboarding & kayaking (with family) 	
C8	ULL: Present at birth & amputation age 1	<p>Currently using:</p> <ul style="list-style-type: none"> • Running blade • Water leg 	Charitable organisational funding, Government Insurance Scheme (have been accepted	<p>Primary:</p> <ul style="list-style-type: none"> • Soccer (mainstream club) • Athletics (school) 	Swimming (local organisation)

			but have not applied for a prosthesis yet)	Secondary: <ul style="list-style-type: none"> Swimming (self-directed) Tennis (with family) Scooter (with family) 	
C9	ULL: present at birth & amputation age 14	On first "everyday" prosthesis after amputation. Planning to apply for sports-specific prosthesis.	Public hospital funding & Government Insurance Scheme (have been accepted but have not applied for a prosthesis yet)	Primary: <ul style="list-style-type: none"> Walking (social) Secondary: <ul style="list-style-type: none"> Ping pong (family) 	Soccer & football (social)

Table 2 notes: In all cases the, Government Insurance Scheme was the National Disability Insurance Scheme.

5.2. Themes

Three themes, and two sub-themes were interpreted from the data. Final conceptualizations of the themes developed, as well as sub-themes, illustrated with extractions from the interview transcripts are described below and in Figure 1.

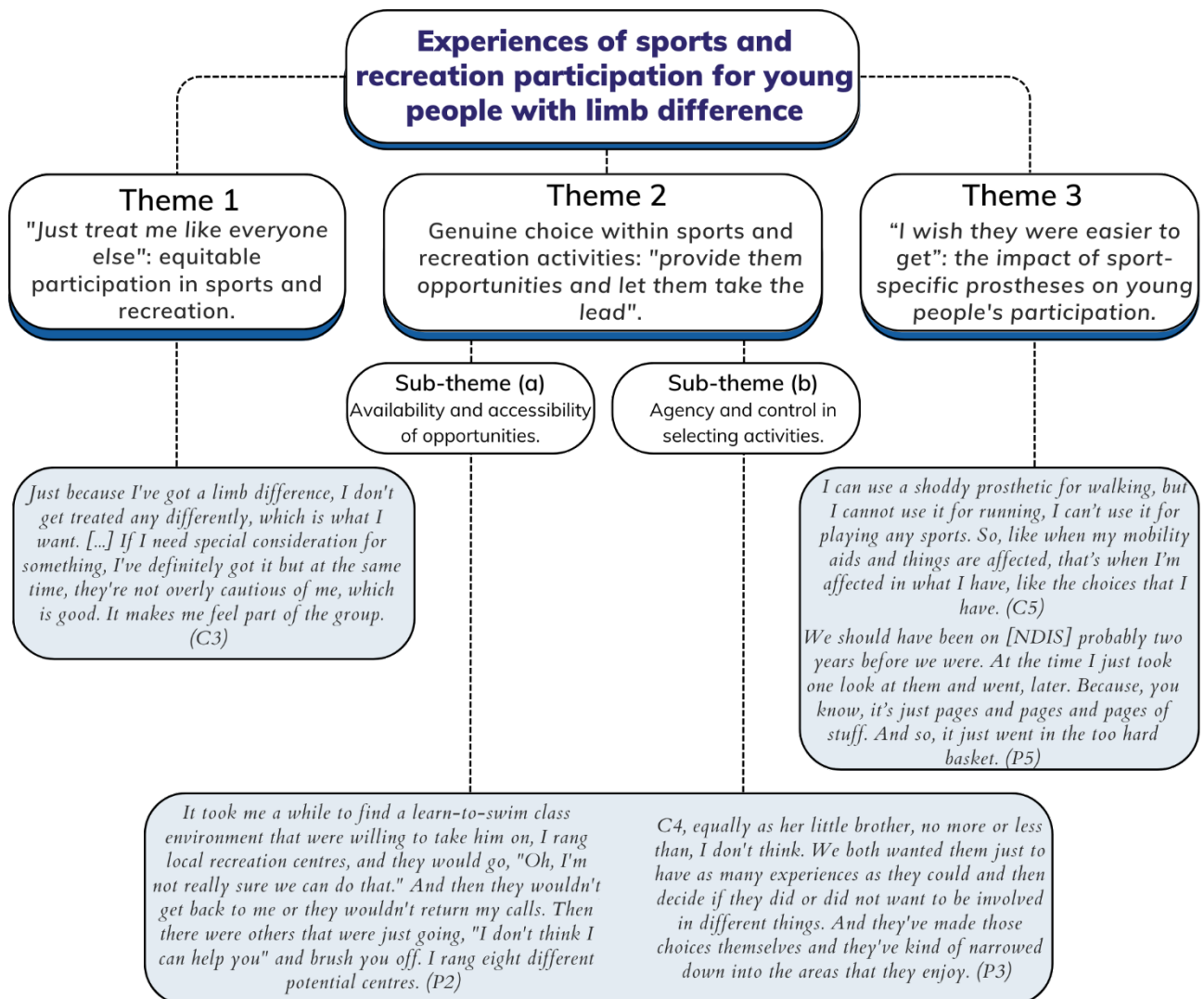


Figure 1: Thematic map.

Theme 1: "Just treat me like everyone else": equitable participation in sports and recreation.

This theme describes the desire of young people with limb difference to be "treated like a regular person" (C1) in their sports and recreation activities. It also explores the need for individualised support and understanding from instructors (i.e., sports coaches, Physical Education teachers, recreational activity instructors) to achieve this equitable participation.

[The coach] is coming to understand how she works and what she will be able to achieve if she's able to keep it up. And so, he's really supportive of his squad [...] And he treats them all equally for what they're doing and what they're achieving [...] Child also doesn't expect any special favours, because she's got a limb difference. She's got to do exactly what everyone does. And she wants to, because she knows that's how she's going to get stronger and faster. (P3)

Many young people and their parents spoke of wanting to be seen by teammates and coaches as "no different" (P1) from their peers regarding expectations of performance. These high expectations for

young people with limb difference were an important part of feeling confident and motivated in their sports participation.

Her teammates just expected her to do exactly the same as what they would do. [...] being included for herself is the important thing. Yes. It does wonders for your confidence (P3)

This desire to not be seen as distinct from peers may manifest differently depending on the sport and context. For example, being seen as an opponent first in a sporting context where other players "*will genuinely play against me without caring about my disability*" (C5) was important to some young people. Whereas one parent described the ease and confidence of their child participating in community sports where she was viewed as a member of the community: "*She doesn't have to explain herself to anyone [...] It sounds weird, but we don't look at her any different. [...] They're just used to her and she doesn't really do anything differently*" (P6).

To support these equal expectations for young people with limb difference, participants noted that having individualised support when needed was important to facilitate their equitable participation.

Some coaches I've had, not necessarily my current one, but maybe they haven't been as focused on the needs of individual athletes. They've been more kind of focused on like, "This is what we're going to do. Let's just all do it," rather than taking time to see what everyone needs individually. So, that can negatively impact on how much they enjoy training with that coach and how much they get out of it as well [...] in terms of my disability, [my coach] has been really open to talking about what I can specifically do to improve my running. And he's been very supportive of the prosthetic and trying that out. So yeah, he definitely understands that my needs might be a little different to the other athletes sometimes. (C4)

Participants noted the balance between coaches providing individualized support for the young person to develop expertise in the sport while maintaining an environment of inclusion and full participation. When coaches were able to negotiate this tension with expertise and subtly, young people and their parents reported a positive influence on sports and recreation participation.

[The yoga teacher] was amazing at just seeing what C1 could do and keeping the rest of the class going. She'd just go and get a block or go and get an elastic or something and just go, "Oh, here you go. Try that, C1." And give her something that was using the right muscle groups but that was appropriate for her. (P4)

Just because I've got a limb difference, I don't get treated any differently, which is what I want. [...] If I need special consideration for something, I've definitely got it but at the same time, they're not overly cautious of me, which is good. It makes me feel part of the group. (C3)

This was also demonstrated when instructors took time to get to know the young person in a one-on-one setting before engaging them in the sports activity. This enabled the instructor to provide modifications as needed swiftly and appropriately for full participation.

The soccer coach, before he threw her in the deep end, he did spend a bit of one-on-one time just getting to know her capability, like "Show me if you can do this," or "how do you do this for me, can you copy what I do?" And just to gauge what he could and couldn't do with her [...] I think she just had that solid time to build up a bit of confidence and go "Yeah, I'm good at this". And then guide her into the group. So, I think it was just him getting to know her and ask questions, which was good because he didn't just pretend there was nothing wrong either. He actually acknowledged that he did have to do things a bit differently. Not just sweep it under the carpet. (P6)

Coaches with specific knowledge regarding para-sports were described by young people and their parents as facilitating sports participation. But equally, for coaches without experience in para-sports, a desire to learn about the young person and their capabilities was also valued: "*a coach that*

understands, or is willing to learn para-sports so that he can guide that child correctly and tell them, what does the future look like?" (P2). The converse was also described, with coaches who were not willing to invest the time, or who "see the challenges and don't problem solve through them" (P2) described as a barrier to sports participation for young people with limb difference. Another barrier to sports and recreation participation described by many young people and their parents was "being underestimated" (C6) by coaches and teammates. Assumptions regarding the young person's ability sometimes led to them being "discarded" (P2) in sporting contexts.

When we got to the regional cross country in year six, [the PE teacher] had had him for five or six years and she watched him run. She said, "He can run!" And I looked at her and I said, "Yes, he can. That's because we've been teaching him because he hasn't had a lot of opportunities at school" and she was completely gobsmacked. (P1)

He's quite a good little swimmer and his swimming teacher was like, "I wasn't sure if he'd be able to participate and he's really, really good". I'm like "Yeah, he's a good swimmer" [laughs]. So, I think that sometimes people make assumptions and then they're surprised because he's quite good. (P7)

In summary, this theme described how expectations of young people's sports performance should be equal to that of their peers without limb difference. Coaches who have knowledge regarding para-sports or are willing to work with the child to learn how to provide individualised support appropriately and subtly are key facilitators to equitable sports and recreation participation for young people with limb difference. This concept of equal expectations, and equitable support for participation, links to the next theme of Genuine Choice, which describes the importance of equitable access to opportunities.

Theme 2: Genuine choice within sports and recreation activities: "provide them opportunities and let them take the lead".

This theme describes how participants viewed genuine choice as consisting of availability and accessibility of opportunities (subtheme (a)), and agency of the young person in influencing activity selection within the available sports and recreation opportunities (subtheme (b)).

Subtheme (a): Availability and accessibility of opportunities

Young people's access to opportunities is strongly influenced by sports and recreation organisations, such as schools, community sports, and clubs. Access was impacted (either positively or negatively) for some families based on "how receptive" (P4) organisations were to engaging the young person in their activities.

It took me a while to find a learn-to-swim class environment that were willing to take him on, I rang local recreation centres, and they would go, "Oh, I'm not really sure we can do that." And then they wouldn't get back to me or they wouldn't return my calls. Then there were others that were just going, "I don't think I can help you" and brush you off. I rang eight different potential centres. (P2)

When describing an opportunity to participate in a mountain bike activity in New Zealand during a school trip, one parent contacted the host organisation to facilitate their child's involvement: "These guys were all over it and they said, "Yeah. We know exactly what you're talking about. We can get this set up." And so, they specially set up a bike for her. She took over her prosthetic. They helped her fit it to the grips. And off she went" (P3).

Another way that organisations can influence participation in sports and recreation activities for young people is by restricting, or promoting, access to activities. One young person described their sporting opportunities as being restricted to the "laziest sports" (C5) at school. They described how negotiating further opportunities was a "discouraging" and "really patronising" (C5) experience. Conversely, organisations providing "lots of information about how you can get involved, and just being really open about getting kids with disabilities involved" (C4) was described as a key facilitator for promoting sporting opportunities. Furthermore, organizational information and support regarding future pathways in sports for young people with limb difference, such as becoming classified for para-sports, opened up access to sporting opportunities for many young people.

Triathlon Australia from day one went, "What do you need? How can we help you? Would you like us to help you find a suitable coach? We believe with the right training, and if C3 has a passion for it and he embraces the sport, he could potentially have a pathway to 2024 Paris Paralympics." [...] it was just like a big warm hug [...] You're in the loop [...] so you can actually see what the future looks like. (P2)

However, being provided with information, but not the organisational support to act on it, was a barrier to accessing sporting opportunities for one family.

[The teacher] sent this thing home which was about getting classification for swimming and athletics. And I sort of investigated, but it was really complicated and the pathway for athletics was quite different from the pathway for swimming. I remember sort of getting really cross about it" (P4)

The sporting expertise and preferences in the family unit also influenced access to opportunities for young people. Some parents spoke of sport having "always had a big role in our family" (P3) and how this led to a desire to provide their children with many sporting opportunities: "from a fitness perspective and a health perspective [...] being in a team and all that sort of stuff, they are just great life skills to kind of develop and have" (P9). Furthermore, many participants described adaptive equipment made by family members to facilitate access to sports and recreation activities.

When she started riding her bike, we thought that it would be more safe for her to have two points of contact on the handlebars. [Her dad] hack-sawed off the funny little hand that was on the end [of the prosthetic] and put some sort of screws and bolts and made some plumbing pipes, so it would attach to the handlebars so that she could feel more secure and steady. [...] He just puts his mind to it and thinks, "Right. How can we sort this out?" So, that's the way he's always tackled any obstacles. So, then nothing's an obstacle. It was just about finding a way around it. (P3)

In summary, this sub-theme described influences on access and availability of sports and recreation opportunities for young people with limb difference. The following sub-theme expands on the theme of Genuine Choice by exploring young people's agency in their selection of sports and recreation activities.

Sub-theme (b): Agency and control in selecting activities.

Within access to equitable opportunities as described above, it is essential for young people to have agency to make choices regarding participation based on self-determined criteria e.g., enjoyment, expertise or functional elements of the activity that increase safety or comfort.

C4, equally as her little brother, no more or less than, I don't think. We both wanted them just to have as many experiences as they could and then decide if they did or did not want to be involved in different things. And they've made those choices themselves and they've kind of narrowed down into the areas that they enjoy. (P3)

Parents often described their children's resilience and grit which facilitated perseverance and agency within sporting activities, even in the face of challenges.

For him essentially it was kind of saying, my decision and the way I do life is I want to live my life without limitations. So I think for him, it's kind of this idea that, yes that he's not defined by sort of his disability but he just, there is a determination and a focus on what he wants to do and he just kind of gets on and he does it. So, and sport has been that beautiful kind of, I guess vehicle that's kind of enabled him to sort of get there. (P9)

He said "Can you spend pocket money on whatever you want?" And I said, "Yeah, whatever you want, it's fine." And he said, "Good. I'm spending mine on the entry fee for the triathlon." [...] So I guess to me that story is indicative of, this has been C3s journey, this is C3s desire. C3 is the one that's pursued this and he fell in love with it. He won of course... in the adult section. (P2)

Agency in participation included young people choosing sports where they felt "powerful" (C5) and were able to demonstrate competence and expertise in their sport both individually and alongside peers.

I loved it, I really did. I felt so powerful and competent, and I really got so much out of it because I could tell when I was improving. Like, I would be sparring with "Billie", who is the best on the team, and one of the other teachers. (C5)

There have been instances where C6 has come home from school, and he's really enjoyed PE lessons because he's felt really competent at doing it. So, they did a unit on gymnastics last term, and he's got really, really good core strength. So, there were a number of things that he could do equal or better than the able-bodied kids in the class. And that made him feel really good because he could demonstrate expertise and we all love to be good at things. [...] So, I think that demonstration of expertise is really important. (P7)

Young people often enacted agency to choose activities based on their peers' involvement or chose to continue their involvement in sports and recreational activities due to their social connections with teammates.

I've made some really close friends through running. So, I see them a few times a week, and we really kind of... It's competitive, but it's not too competitive. We push each other and try to motivate each other. And it's really helped in my training becoming friends with the people in my squad. And we meet up outside of training as well, which is good. (C4)

Particular functional elements of sports played a role in activity preferences and choices for many young people. For example, one participant chose sports with natural rest breaks to assist in alleviating pain and fatigue, and another chose a sport where their risk of injury was lower. Others chose sports that meant they didn't require a prosthesis or adaptations as *"It's time-consuming to do that kind of thing [...] my friends don't have to think about that."* (C1)

The big problem in basketball is that there's stealing and if I'm not careful, if somebody was stealing the ball, I could just dislocate my elbows quite easily ... [In netball] there's not as much falling over, I don't have to worry about catching myself when I fall, or dribbling the ball up and down the court and tripping on it. (C1)

We've also got a sea kayak for him [...] it's kind of an ideal activity because it's not dependent on prosthetics or legs or lower body particularly. (P9)

In summary, these two sub-themes describe how genuine choice influences participation in sports and recreation activities. Genuine choice is described by participants as both access and availability of opportunities, and young people's agency in their selection within available sports and recreation activities.

Theme 3: *"I wish they were easier to get"*: the impact of sports-specific prostheses on young people's participation.

This theme describes the impact of sports-specific prostheses on sports and recreation participation for young people with limb difference, and links back to the previous two themes of equitable participation and genuine choice. Sports-specific prostheses enable equitable participation alongside peers and facilitate genuine choice within different sporting opportunities: *"it certainly changed his capacity to access sport"* (P1).

I can use a shoddy prosthetic for walking, but I cannot use it for running, I can't use it for playing any sports. So, like when my mobility aids and things are affected, that's when I'm affected in what I have, like the choices that I have. (C5)

[The prosthesis] has allowed me to run a lot easily, walk a lot easier. It's been good for pretty much everything. [...] There was a certain limit I could do on the water leg. [...] I run faster. I do a lot more running and I'm just a lot more active. (C6)

In addition to enabling access to sports and recreational opportunities, the correct prosthesis also reduced pain and increased comfort and safety while participating.

[The prosthetic] does allow her that involvement in something that would be potentially dangerous. We've got some very good mountain bike tracks around us, and she can tackle them very well on her bike. And she doesn't hold back. And so, we would be reluctant to allow her to do that without it being safe, and this makes it safe for her. (P3)

Prostheses also played a role in enabling young people to feel *"stronger"* and *"more confident"* (C4) and to reach their full potential in their chosen sport.

With the running prosthetic, I think they've become an enhancement for her. It's like any athlete. It's like Thorpey with his swimsuit. She's doing the hard work, and this is to improve and hone her own abilities. And hopefully by getting, tweaking those little bits and pieces, and giving her more drive on the left side and it's helping her block starts and et cetera. So, she would still be participating without that, but this will allow her to reach her full potential. (P3)

Furthermore, multiple prostheses due to rapid growth and to allow access to multiple sports and recreation opportunities were often essential for young people: *"C2 has had three legs in the last 11 months because he's grown so much."* (P1)

Accessing sports-specific prostheses to facilitate access and involvement in sporting opportunities was described as strongly reliant on obtaining funding. Parents described the funding as coming primarily from the National Disability Insurance Scheme (NDIS) and charitable organisations such as the START Foundation. Participants spoke positively and with great appreciation for funding processes through the START Foundation, however there were mixed experiences with the NDIS. Some parents described the NDIS as *"a really horrible process to apply"* and not *"applicant-centric"* (P4) whereas others felt it was *"really easy"* (P5). However, for those parents who reported the process easy, one was a professional administrator and the other explained *"we should have been on it probably two years before we were [...] at the time I just took one look at them and went, later. Because, you know, it's just pages and pages and pages of stuff. [...] And so, it just went in the too hard basket"* (P5). The focus on highlighting their child's barriers to participation during the process was distressing for some parents: *"you have to sort of say all the things that they can't do that you want them to be able to do which is... you know, that can be a bit upsetting"* (P8). One parent had never sought access to prostheses due to the burden of both applying for funding

and trialing the prosthesis and wished for *“the opportunity to explore those possibilities and having much easier and freer access to that kind of thing.”* (P4)

Some parents described the process and outcome of NDIS funding as being *“at the mercy of the knowledge of the people that you’re hooked up with”* (P5). When the *“connecting person”* (P8) (local area coordinator (LAC)) was able to support, advise and advocate for the essential nature of sports-specific prosthesis, families felt the process was manageable. However, one parent reported:

We have an NDIS contact person and she’s trained in social work or something, so she doesn’t know anything about prosthetics and neither does her manager, so she tries to help us, but I have to sort of gather reports to give to her [...] I write something myself, which I think explains things pretty clearly, so I give it to her and then she has to then pass that on, so you know, that’s a barrier if she gets it wrong [...] I often have to chase that up and then you find out that they’ve accepted it, but they haven’t bothered to tell anyone which is quite frustrating, it’s like I don’t know who I’m supposed to get the information from [...] If you’re not confident and educated and articulate, I don’t know how you advocate for your child without having a mental breakdown (P8).

The dependence of the process on reports from medical experts was a frustration for some parents who reported that *“as a parent, you’re quite disempowered to make a suggestion”* (P4).

In summary, this theme described the impact of sports-specific prostheses on sports and recreation participation for young people with limb difference. Young people spoke of prostheses enabling increased access to, and choice of, sports opportunities, as well as facilitating them to excel within their chosen sports. Parents described mixed experiences with accessing funding to support the acquisition of sports-specific prostheses. The complexity of requiring different prostheses for different sports as well as catering for growing bodies was compounded by often frustrating, confusing, and time-consuming processes that devalued their experiences and knowledge of their child's needs.

5.3. Mapping experiences using the Socio-Ecological Model

Within the three themes described above, there were clear barriers and facilitators to sports and recreation participation for young people with LD. Mapping these using the socio-ecological model (Dahlgren & Whitehead, 2021), it is clear that family dyads experience barriers and facilitators across all four levels of this framework (Figure 2). This is significant as it points to the need to intervene across multiple levels to effectively identify opportunities to improve, and sustain, participation in sports and recreation (Kilanowski, 2017; Martínez-Andrés et al., 2020; Mehtälä et al., 2014).

Key influences on participation in sports and recreation for young people with limb difference

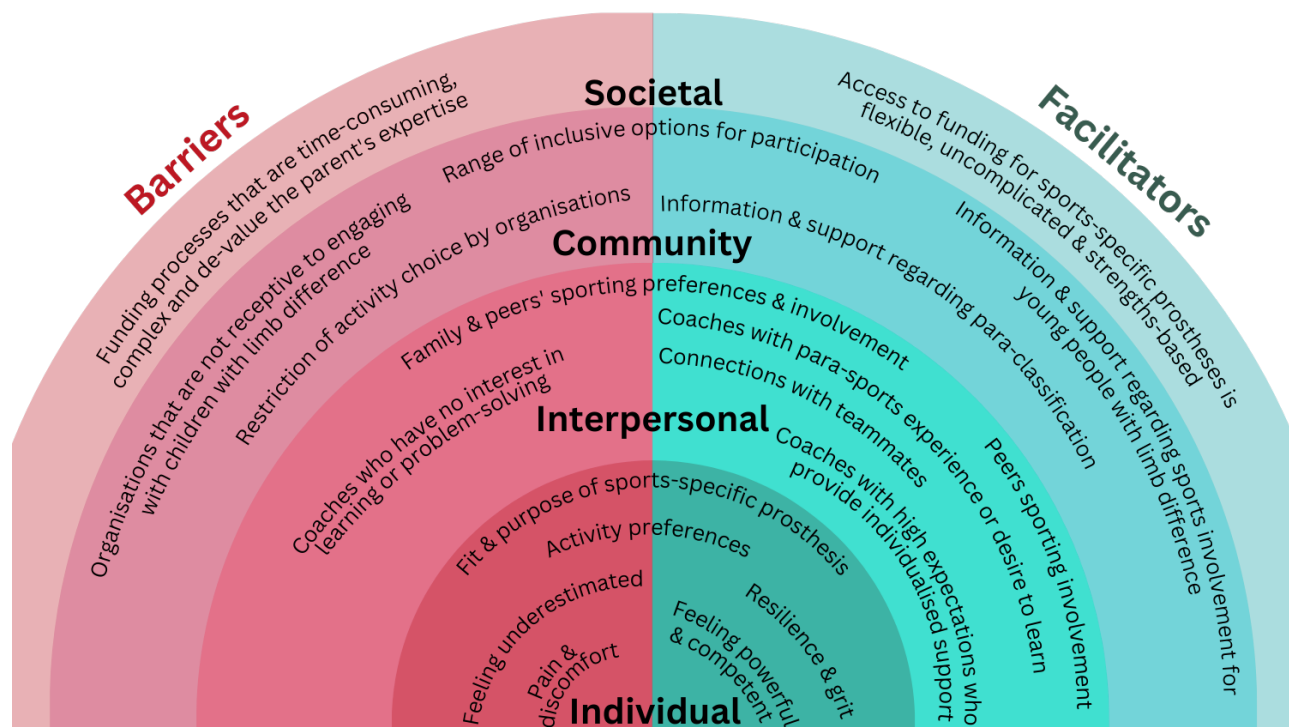


Figure 2: Barriers and facilitators influencing sports participation for young people with limb difference. *Note: the term coaches used in this figure refers to all personnel instructing or teaching sports & recreation activities in schools or external organisations including physical education teachers and sports coaches.*

At the **individual level**, the comfort, fit and functionality of the sports-specific prosthesis acted as both a barrier and facilitator. If the fit of the prosthesis was good and it was comfortable to wear, then it was a facilitator to participation. Conversely, if the young person had grown out of the prosthesis, or if there were other influences causing discomfort, it reduced participation. Similarly, if the purpose of the prosthesis did not match the sporting requirement (e.g., wearing a heavy 'everyday' prosthesis for athletics) then it acted as a barrier, whereas having an appropriate prosthesis (e.g., a blade for athletics) supported participation. This finding was also mirrored in Canadian and Dutch contexts, where the functionality of the prosthesis also acted as both a barrier and facilitator to engaging in sports for young people (Ahmed et al., 2018) and adults (Bragaru et al., 2013) with LD.

Being in pain (e.g., stump pain or phantom limb pain) also reduced participation in sports and recreation at individual level in the current study, and this was mirrored in Bragaru et al.'s (2013) study. Lastly, the current study found that feeling competent in activities was a major individual facilitator to participation, as was the resilience and grit of young people and their families in pursuing participation in sporting opportunities.

At an **interpersonal level**, coaches were a key influence on sports participation. Specifically, coaches who had prior experience in working with para-athletes, and therefore who had high expectations and an understanding of how to provide appropriate support for young people to meet these expectations, were viewed as facilitating participation. Also viewed as supporting participation were

coaches who although may not have specific experience, were open to learning and working with the child and family to overcome barriers and support meaningful sports participation. The key barrier at this level were coaches who were passive, or had no interest in working proactively with the young person and their family to "*problem-solve*" through to meaningful engagement. Peers and family members were also influences at the interpersonal level, as their sporting preferences and level of involvement acted to influence the activities young people were exposed to, and the choices they made. The impact of coaches and peers was also found to influence young people's participation in a Canadian context, where the coaches understanding of the child's ability acted as a barrier or facilitator depending on the depth of their knowledge and insight (Ahmed et al., 2018). Furthermore, this Canadian study also noted how peers treating the young person as "*no different*", supported participation (Ahmed et al., 2018, p. 1396).

At the **community level** the key influences on participation were organisations offering sports and recreational programs, including schools, community-based organisations, and specific sporting bodies. Organisations could facilitate young people's participation by providing both information and active support for young people and their families regarding programs available, and para-sport classification. Organisational barriers included restricting activity choices for young people with limb difference, as well as not being receptive to engaging and working with these young people and their families.

Parents in a Canadian study also described needing to "*set the stage*" (Ahmed et al., 2018, p. 1396) for their child's participation, by both mapping the sports and recreation opportunities available, and providing education to the organisation and coach. A Dutch study also found that a lack of available sporting opportunities impacted participation for adults with LD (Bragaru et al., 2013). Furthermore, Bragaru et al.'s study found transportation to be a barrier to accessing sporting opportunities, but this was not directly described by parents or young people in the current study.

The key influence on sports and recreation participation at the **societal level** was access to funding in the current study. Families accessed funding to support purchase of individualised equipment through multiple avenues (see Table 2). Funding processes that were flexible, timely, and responsive to changing needs (e.g., growing bodies and changing or multiple sports preferences) supported sports and recreation participation. Processes that were complicated, de-valued parent knowledge, or were framed with a deficits-based lens, presented a significant barrier to supporting participation.

A study set in Canada (Ahmed et al., 2018) also found that costs (both financial and time) presented a significant influence on sports participation for young people with LD. Furthermore, they reported that stigma (primarily teasing from peers) related to using a prosthesis also impacted sports participation. Stigma was also discussed as a barrier for adults with LD in a Dutch study (Bragaru et al., 2013). During interviews for the current study, stigma was not discussed, however it did come up in a member-checking response, where a parent voiced "*If there is a culture of inclusion or exclusion re: disability, that can make all the difference*" (P4).

5.4. A conceptual model for practice and policy

Synthesis of the three themes described above, the broader literature, member checking feedback, and experiences of the research team, resulted in development of a conceptual model that can be used in practice and/ or policy. Figure 3 illustrates the model: "Moving through childhood: The cycles of participation supports for young people with limb difference".

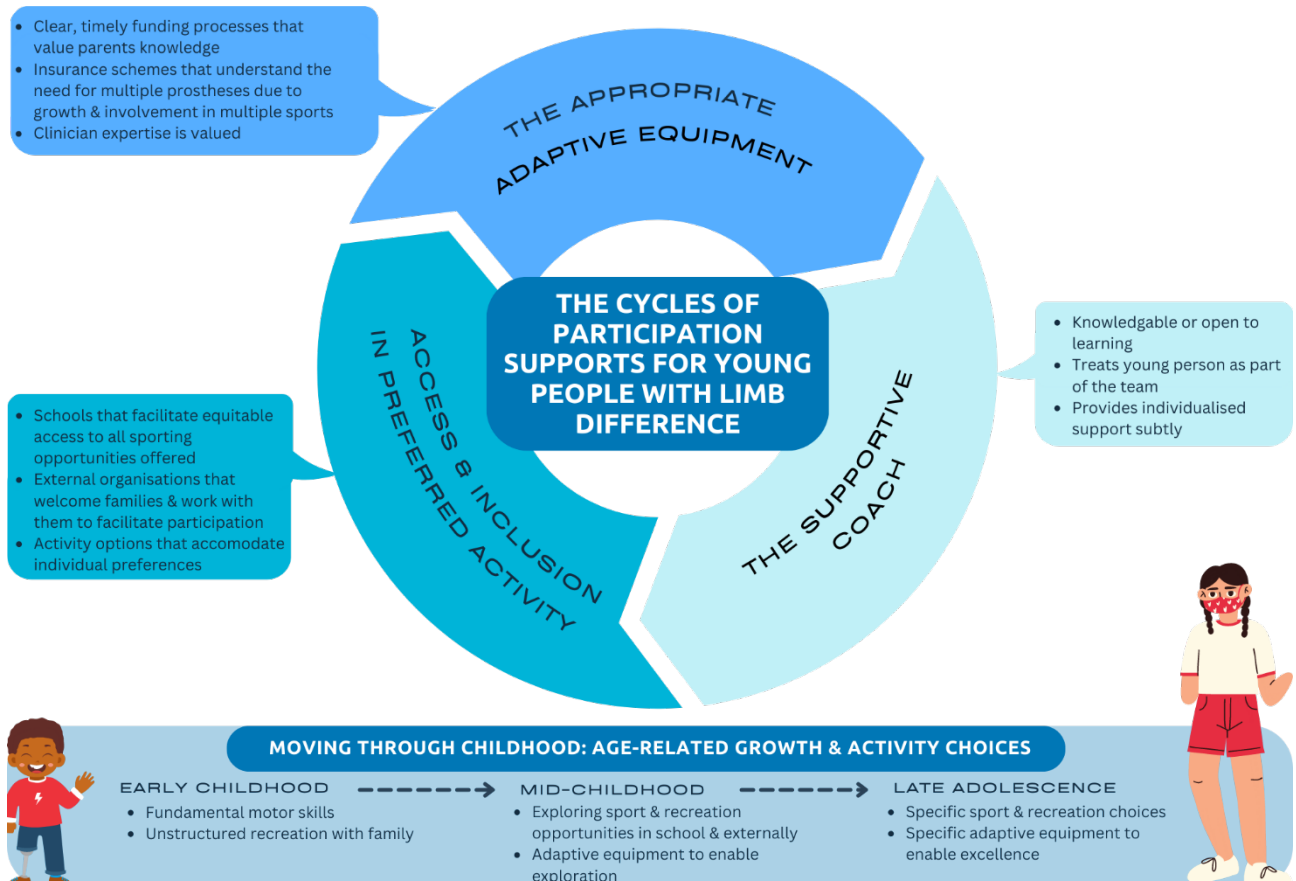


Figure 3: Moving through childhood: The cycles of participation supports for young people with limb difference. *Note: the term 'coaches' used in this figure refers to all personnel instructing or teaching sports & recreation activities in schools or external organisations including physical education teachers and sports coaches. The term 'adaptive equipment' was chosen due to its use in interviews, literature, and member check responses, and includes both sports-specific prostheses and customised modifications.*

6. Implications for practice

This study found that the experiences of young people with limb difference in participating in sports and recreation in an Australian context, and the perspectives of their parents, included a desire for equitable participation and genuine choice, and highlighted the impact of sports-specific prostheses. Furthermore, barriers and supports to participation in sports and recreation were identified across all four levels of the socio-ecological model (Dahlgren & Whitehead, 2021). Lastly, the interpretive approach applied in this project enabled a conceptual model to be developed for application to practice (Thorne, 2016). "Moving through childhood: The cycles of participation supports for young people with limb difference" is a model that aims to inform key stakeholder groups on how to apply the findings of this study to support sports and recreation participation for young people with LD. These key stakeholder groups include: funding bodies, clinicians, organisations and coaches

delivering sports and recreational programs (including schools and teachers), and importantly, young people with LD and their families.

First, understanding the impact of '**Age-related Growth and Activity Choices**' for funding bodies and the people involved in supporting funding distribution (e.g., Local Area Co-ordinators for the National Insurance Disability Scheme) is essential. Access to funding needs to cater for the rapid growth period that young people transition through over their childhood. This means clear and supported application processes and timely approvals and reviews to ensure that '**The Appropriate Adaptive Equipment**' are funded expeditiously to keep pace with the young person's growth-related changes. Furthermore, in early childhood, funding can support prostheses and other individualised equipment that supports unstructured recreation with family. However, in later childhood, enabling access to funding for multiple prostheses (either to support exploration of different types of activities or for high-level performance in multiple sports) is a key consideration for funding bodies.

Another key consideration in accessing 'The Appropriate Adaptive Equipment' to enable sports and recreation participation for young people with LD, is engaging the expertise of clinicians. Clinicians such as prosthetists and orthotists provide both essential services related to ensuring the correct fit and purpose of prostheses, as well as key information for funding applications. Clinicians can play a role in advocating for timely provision of funding, as well as the need for multiple prostheses to support exploration and variety of sporting activities.

Organisations that offer sports and recreation opportunities, as well as the coaches or teachers that deliver the programs, can also utilise *The cycles of participation supports for young people with limb difference*. Firstly, organisations that welcome the young person and their family, offer equitable access to all programs they run, as well as working actively with the young person and their family to facilitate their participation, are well positioned to ensure '**Access and Inclusion in Preferred Activity**' for young people with LD. Within these organisations, '**Supportive Coaches**' play a key role in facilitating participation for young people. Coaches who demonstrate a willingness to learn, or who have experience in working with para-athletes, can support young people with LD to engage meaningfully in sports and recreation. Furthermore, finding the balance between providing individualised support to the young person, while ensuring they feel part of the team, is an essential skill for coaches.

Lastly, we hope that parents and carers and other advocates for young people's participation can use this model in discussion with all stakeholders described above to draw attention to the key influences and strategies that can be used to support equitable sports and recreation participation for young people with limb difference.

6.1. Considerations for interpretation

There are some important characteristics of this study that may have influenced the interpretation of the results. First, all parents that were recruited were mothers. Therefore, the perspective of caregivers that identify with a fathering role are missing, which may mean this study is lacking important experiences that could shed further light on the young person's sports and recreation participation.

Second, data collection for this study commenced during the COVID-19 pandemic. The first six dyads were interviewed when sports and recreation were restricted, and thus were asked to recall

their pre-restriction experiences. Recalling experiences may result in discussion of particularly impactful memories, rather than illustrating a more typical day-to-day experience. And third, although this study aims to represent experiences in an Australian context, eight of the nine dyads interviewed come from one Australian state (Victoria). This is particularly important given that sports and recreation restrictions during COVID-19 were the most limited in Australia.

Lastly, it is important to understand how the analysts may have influenced interpretation of the data. CI Toovey is a physiotherapist and researcher who is committed to working with individuals and communities to create supportive environments for physical activity for children with disability. While she has over 10 years' experience working with paediatric populations, her experience of working with children with limb difference is limited. CI Toovey has worked with adults with limb difference in her role as a paracycling classifier. This lack of experience with children with limb difference on one hand may mean some of the important aspects of the data could have been missed, but also means fewer assumptions of the data may have been made. CI Toovey's experience as a classifier in elite paracycling means there is a risk that this formed part of the lens for interpreting the data. AI Coulston is a physiotherapist and researcher with a passion for enhancing equity and inclusion in sports and recreation for people with disability. She is new to working with people with limb difference and took time to familiarise herself with the literature in the area as well as discussions with members of the research team to work with the data in a more informed manner. It is possible that due to her lack of clinical experience in this area, she may have missed or minimised important aspects of the data. However, the collaborative approach to analysis as well as the input and expertise of the wider research team lowers this risk for both analysts.

7. Conclusion

This qualitative study developed three primary themes from 18 interviews describing the experiences of young people with limb difference in participating in sports and recreation in an Australian context. Themes described equitable participation and genuine choice in sports and recreation, as well as the impact of sports-specific prostheses on young people's participation. Barriers and facilitators to sports and recreation participation were identified across all levels of the socio-ecological model. This demonstrates the need for strategies at individual, interpersonal, community and social levels to support participation for young people with LD. A conceptual model "*Moving through childhood: The cycles of participation supports for young people with limb difference*" illustrates how key stakeholders can apply the findings of this study to their practice in supporting young people with LD and their families.

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Appendix A: Interview guides for dyads

* Numbered questions are the core questions, lettered questions are follow-up prompts if needed*

A.1: Interview guides for parents

Opening statement:

Hi [insert name of interviewee] thank you for agreeing to do this interview. Before we get started I want to remind you that we are exploring the experiences of children with limb differences when participating in sport and recreational activities. I'd also like to remind you that doing this interview is voluntary and you may stop at any time. If at any stage you are uncomfortable with a question let us know and you may choose to skip the question or stop the interview. I'd also like to thank you for providing consent in the questionnaire.

I also want to acknowledge the current climate regarding COVID-19 and that it is likely to have impacted your usual sports and recreational activities. So, for most questions in this interview I want you to think about your child's usual participation in sports and recreation, but at the end we will ask some questions about the COVID-19 period.

Do you have any questions before we begin?

Opening question: Today we are going to be talking about your experiences in sport and recreation, what role does sport and recreation play in your lives?

Questions for parents of children who do use sports prostheses:

1. Please describe, if any, sports and active recreation activities has your child been involved in over the past 2 years? This may include sports like netball, soccer, or gymnastics or things like bike riding, dancing or circus arts
 - a. Tell me about any notable experiences in sports your child has done over the course of their life?
 - b. Was it through mainstream organisations or specifically for children with LD or other disabilities?
 - i. Can you describe any factors that influenced what sports stream your child participated in?
2. Does your child use any adaptive sports equipment? For example, something that is built into the sporting equipment. If so, please describe it for me.
3. How do you think your child's level of involvement in sport impacted you and your family?
 - a. How has having access to a sports prosthesis impacted you and your family?
4. How do you think your child's level of involvement in sport has impacted them?
 - a. How do you think having access to a sports prosthesis has impacted them?
5. Do you think your child's teammates and coaches have influenced your child's sport/rec participation at all? If so, how?
 - a. How have they helped?
 - b. What have been the challenges?

6. Please describe how your child's sports prosthesis is funded
7. What helped you access a sports prosthesis for your child?
8. What obstacles did you experience when getting funding for the sports prosthesis for your child?
9. Does your child use multiple sports prostheses? Can you tell me about how you think the different prostheses help or hinder your child's participation in sport/rec?
10. Do you think your child's activity was impacted by COVID-19 restrictions?
 - a. Do you think their limb difference had any additional impact on this? For example, equipment not being available

Questions for parents of children who don't use sports prostheses:

1. Please describe, if any, sports and active recreation activities your child has been involved in over the past 2 years. This may include sports like netball, soccer, or gymnastics or things like bike riding, dancing or circus arts
 - a. Tell me about any notable experiences in sports your child has done over the course of their life?
 - b. Was it through mainstream organisations or specifically for children with LD or other disabilities?
 - i. Can you describe any factors that influenced what sports stream your child participated in?
2. Does your child use any adaptive sports equipment? For example, something that is built into the sporting equipment. If so, please describe it for me?
3. How do you think your child's level of involvement in sport/rec has impacted you and your family?
 - a. How has not having a sports prosthesis impacted you and your family?
4. How do you think your child's level of involvement in sport/rec has impacted your child?
 - a. How do you think not having a sports prosthesis has impacted your child?
5. Have you tried to get funding for sports prostheses in the past?
 - a. If so, please describe any challenges to accessing funding?
 - b. If not, please describe why not?
6. Do you think your child's activity was impacted by COVID-19 restrictions?
 - a. Do you think their limb difference had any additional impact on this? For example, equipment not being available

A.2: Interview guides for young people

Opening statement:

Hi [insert name of interviewee] thank you for talking to me today. I'd like to have a chat with you about how you participate in sport, games or other physical activities. You don't have to do this interview so if you want to. You can stop the interview at any time. I'd also like to thank you for agreeing to talk with me today.

If still relevant interviewer will state:

I'm sure you have noticed that a lot of your activities have been cancelled because of the virus. For most questions I want you to try and think about before things were cancelled and what you would usually do, but at the end we will ask some questions about how things have changed because of the virus

Do you have any questions before we begin?

Opening question: Today we are going to talk about sport and recreation, when was the last time you played sport or did something active?

Questions for children who do use sports prostheses:

1. What sports or other active activities do you usually do or have done in the last couple of years? For example, soccer, dance, circus, bike riding
2. Do you use any custom made sports equipment? For example, a specially made saddle for horse riding or bike for cycling. If so, tell me about it.
3. How does playing sport/rec [insert child's specific sport here] make you feel?
 - a. What are the best things about playing [child specific sport]?
 - b. What do you find hard about playing [child specific sport]?
4. Can you tell me a bit about your teammates?
 - a. What things about your teammates that make playing sport fun for you?
 - b. What things about your teammates that make playing sport hard for you?
5. Can you tell me a bit about your coach?
 - a. What things about your coach that make playing sport fun for you?
 - b. What things about your coach that make playing sport hard for you?
6. What things that make it easier for you to do [insert sport]?
7. What things that make it harder?
8. How does having a sports prosthesis change the way you play [insert sport]?
9. Do you think how active you were changed because your usual activities may have been cancelled due to COVID-19?
 - a. How did they change?

Questions for children who don't use sports prostheses:

1. What sports or other active activities do you usually do or have done in the last few years? For example soccer, dance, circus, bike riding
2. So we know you don't use a sports prosthesis for your sport, but do you use any adaptive sports equipment? For example, something that's built into the sporting equipment like a specially made saddle for horse riding or bike for cycling. If so, please describe it for me
3. How does playing sport/rec [insert child's specific sport here] make you feel?
 - a. What are the best things about playing [child specific sport]?
 - b. What do you find hard about playing [child specific sport]?
4. Can you tell me a bit about your teammates?

- a. What things about your teammates that make playing sport fun for you?
 - b. What things about your teammates that make playing sport hard for you?
5. Can you tell me a bit about your coach?
 - a. What things about your coach that make playing sport fun for you?
 - b. What things about your coach that make playing sport hard for you?
6. What things that make it easier for you to do [insert sport]?
7. What things make it harder?
8. Have you ever thought about getting a prosthesis specific for the sports you do? If so, how do you think having a prosthesis would change how you do your sport and other activities?
9. Why or why do you not want a sports prosthesis for your sport?
10. Do you think how active you were changed because your usual activities may have been cancelled due to COVID-19?
 - a. How did they change?

Alternative questions for if they don't identify any sport/recreation

1. Why don't you play sport or do other active activities?
 - a. How would having a sports prosthesis change this?
2. If you were to play a sport or do an active activity would you choose one that needed a prosthesis or one that you could play without one? Why, why not?

Appendix B: AI Villalon's reflection on the results

Themes identified within the results are reflected with my own life experience. It's important to consider that I acquired my amputation when I was 17-years-old whereas all participants included are younger than my first experiences living with limb difference. Some comments within the results are more specific to younger children, while others can be carried on to adulthood.

Theme One – “Treat me just like everyone else”.

- The skill of good coaches balancing the tension between “providing individualized support for the young person to develop expertise in the sport while maintaining an environment of inclusion and full participation” with expertise and subtlety can be applied to the individual with limb difference also. For example, in my experience on going on long multi-day hikes. I've hiked with people who pretend I don't have a disability and expect me to keep up the pace, leaving feeling disempowered. On the other hand, I've hiked with people who underestimate my ability and offer too much help without subtlety, leaving me feeling again disempowered. I've found that since I'm the best one to know my physical abilities, the easiest thing to do is let them people beforehand that if I need help I'll let them know, otherwise assume I am capable. It gives me the autonomy over how I am treated. Over time people I regularly hike with have learnt what I need help with, help in a more subtle ways and sometimes I no longer need to ask.
- One thing that I have found helpful to identify what I am capable of, is participating in events and sports with other people who have a similar disability and are a similar age. Seeing others play sports well motivated me to give certain things ago which I previously thought I couldn't do because of my disability.
- For a young person who may have not yet developed the skill of identifying and communicating what they need help with, getting to know the young person and their abilities one-on-one would be invaluable in their ability to participate in their sport to their full potential.

Theme Two – “Provide them opportunities and let them take the lead”.

Sub-theme A – “Availability and accessibility of opportunities”.

- In my experience within sport, there was a noticeable difference in access between sports that were disability-specific and those that were not. Disability-specific sports such as wheelchair basketball and adaptive climbing groups required me to travel large distances to compete and train. This was not the case in able-bodied sports I participated in. I did not compete in able-bodied sports at a competitive level which may influence my comparison between the two.
- I have been able to access any able-bodied sport that I have wanted to in my lived experience but not without a good amount of problem-solving. Working as a clinical prosthetist allowed me to address functional problems regarding my lower-limb prosthesis directly. There were many brain-storming discussions with colleagues, family, friends, the guy at the bike shop, and a lot of trial-and-error. This has resulted in solutions like putting a toe clip on my bike pedal so my prosthetic foot does not slip off, or creating a prosthetic foot specific for rock climbing.

Sub-theme B – “Agency and control in selecting activities”.

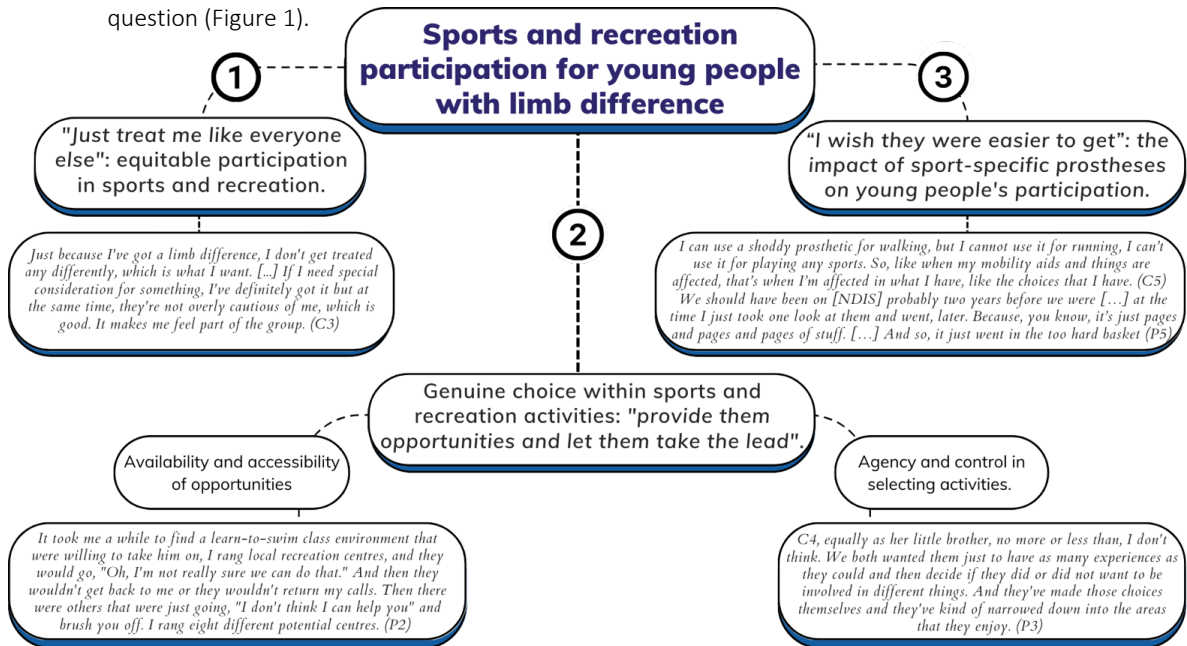
- I have not been denied access to any sporting activities if I wanted to participate in them.
- I have let rate of injury in a sport determine what sport I chose. For example, I began rock climbing with some friends. When it comes to choosing to either top-rope climb or boulder, I chose to top-rope as I wanted there to be less likelihood of be injuring my contralateral limb. Doing so would significantly impact my activities of daily living.

Theme Three- “I wish they were easier to get”.

- My experience with NDIS has been both good and bad. Good in that without the NDIS I wouldn't have access to sport-specific prosthetic feet like my running blade except through applying for grants. Bad in that the process of getting funding approved for prosthetics can take months and it can be confusing to navigate.
- I have been in the fortunate position of having easy access to knowledge regarding the NDIS and it's process whilst working in the prosthetics industry but this is not the case for most. It's not uncommon for your assigned Local Area Coordinator to not fully understand what is needed to have adequate prosthetic care and participants need to be able to articulate well what is needed.
- Waiting times for approval of funding vary. I've experienced waiting months to have a prosthesis approved by the NDIS and I can imagine it would be more frustrating for younger people with limb difference because by the time the funding for the prosthesis is approved, they've already grown so much that their socket may not fit well anymore, or their prosthetic prescription is no longer appropriate.
- Having sport-specific prostheses has dramatically increased my enjoyment of sport and has allowed access me to participate well in my chosen sports. For example, I instantly felt more balanced and symmetrical when I ran on my running blade. It felt more natural, and I could focus less on comfort and more on running further distances.

Appendix C: One-page summary for member-checking process

The research question for this study was: How do young people with limb difference experience sports and recreation participation? Three main themes (patterns) were developed from interviews with young people and their parents that aimed to answer this question (Figure 1).



In addition, Figure 2 illustrates the barriers and facilitators to sports participation for young people with limb difference identified during interviews.

Key influences on sports participation for children with limb difference

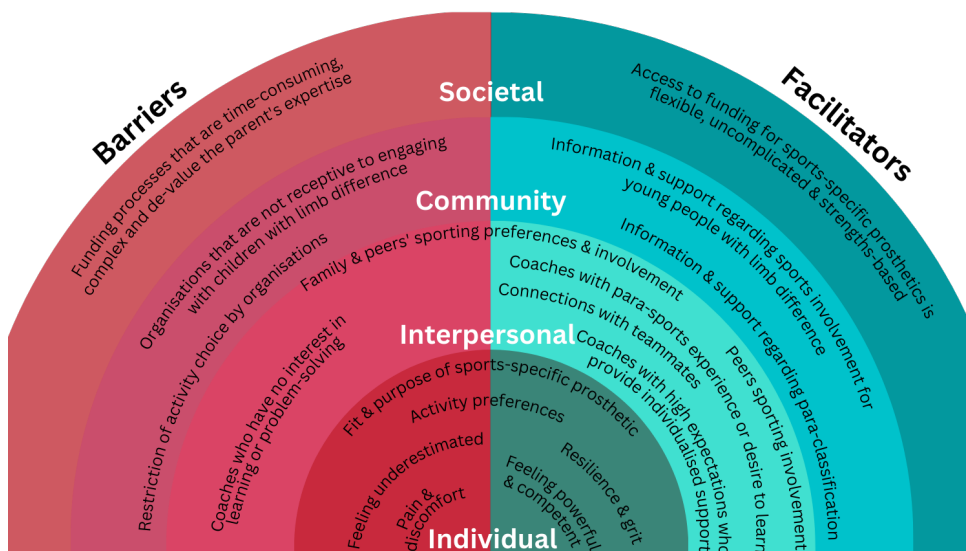
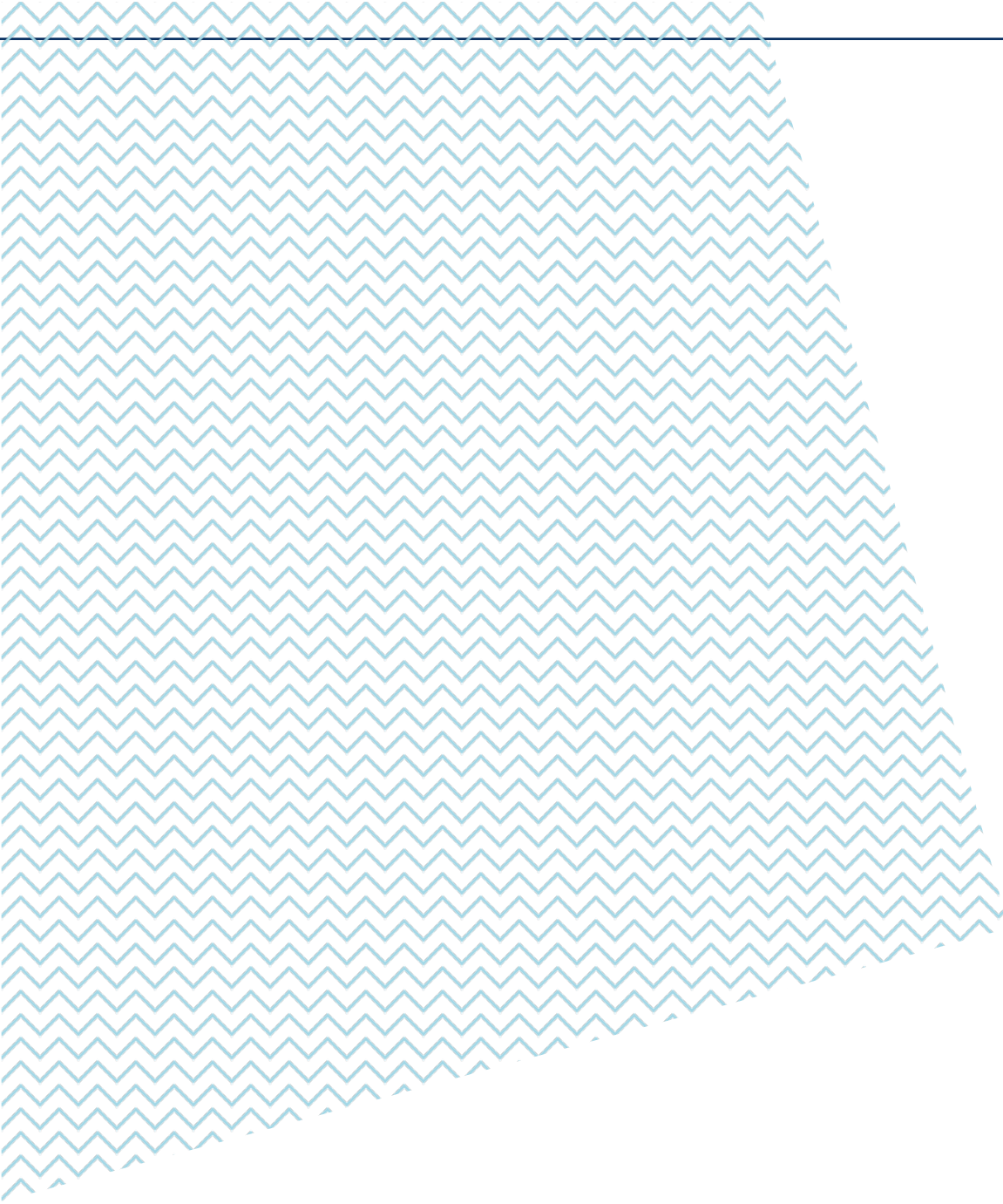


Figure 2: Barriers and facilitators influencing sports participation for young people with limb difference.



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