

Title: The meaning of leisure to children and young people with significant physical disabilities: Implications for optimising participation

Abstract:

Introduction: Facilitation of meaningful leisure participation for children and young people (CYP) requires an understanding of what leisure means to them. This study aimed to understand meaningful leisure from the perspective of CYP with complex physical and communication disabilities.

Method: A hermeneutic phenomenological research design was used. Data was gathered through multiple interviews with six young people supported by photo elicitation, Talking Mats and direct observation. Individual case studies were analysed together with six autobiographies of people with similar disabilities. Data analysis was iterative and multi-directional, alternating between segments and the whole throughout interpretation.

Results: Leisure experience meanings were uniquely constructed for each person, based on preferences, personality and circumstances. The Tree of Leisure emerged as a useful metaphor for three essential features (control, engrossing, enjoyment) and four key meanings (escape, exploration, exchange, and expression) of leisure. CYP experienced five meaningful outcomes that lasted beyond the leisure activity (restoration, protection, construction, reflection and connection).

Conclusion: For CYP with disabilities, a balanced array of diverse leisure experiences provides a powerful and accessible route to wellbeing. Implications for practice include understanding the individual, focusing on the social environment, supporting self-advocacy and promoting opportunities for free movement.

Introduction:

Leisure has been considered a central occupation important for health since the inception of the occupational therapy profession (Suto, 1998). Children and young people (CYP) with physical disabilities view leisure as essential for their quality of life, yet they have fewer and less diverse leisure opportunities than their non-disabled peers (Shikako-Thomas, Kolehmainen, Ketelaar et al, 2014). National policies on participation and inclusion also require services to consider the views of young people in service design and provision (e.g. Australian Local Government Association, 2016; *Children and Families Act 2014*). Occupational therapists who aim to facilitate meaningful leisure participation need to consider a person's perception of their involvement in that activity (Imms, Adair, et al., 2016), which requires an understanding of what leisure means to the young people themselves. The purpose of this study was to understand meaningful participation in leisure from the perspective of CYP with complex physical and communication disabilities.

Literature review:

Leisure is recognised as important in itself for living a full life, and is known to contribute significantly to quality of life, both for the general population (Lapa, 2013) and for CYP with disabilities (Dahan-Oliel, Shikako-Thomas and Majnemer, 2012). Leisure is therefore seen both as a desirable outcome, and as a facilitator, of health.

Leisure is valued by CYP with disabilities and their families as a contributor to social and community connectedness (Allard et al., 2014) and identified as a priority area for families (Piškur, Beurskens, Jongmans et al, 2015). Meaningful leisure participation that feels safe, accepting, accessible and inclusive has been identified as a need by families of children with disabilities (Woodgate, Edwards and Ripat, 2012). There is increasing understanding of patterns and determinants of leisure participation, barriers to and facilitators of participation, and leisure preferences for CYP with a broad range of disabilities. Access to leisure for these young people is more challenging, with fewer programmes and services that are considered accessible (Bedell et al., 2013). Children with disabilities often have fewer friends and less contact with peers outside of school (Mundhenke, Hermansson and Sjoqvist Natterlund, 2010). Higher levels of functional impairment are associated with lower levels of participation in leisure activities overall and lower levels of

participation in preferred leisure activities (Anaby, Law, Coster et al 2014; Imms, King et al., 2017) These findings have been replicated across different ethnic and cultural populations (Schreuer, Sachs and Rosenblum, 2014).

Understanding the subjective experience of participation in leisure is critical to truly understanding participation. Imms, Adair and colleagues (2016) have identified two key concepts within participation, firstly the need to attend, and then the need to be involved. Involvement is personally determined and relates to motivation and how it is experienced by the individual. Participation in leisure therefore implies that being physically present for an activity is not sufficient and that a subjective feeling of being involved is necessary. The most effective way to understand what involvement in leisure means to CYP with disabilities is to ask them directly. The views of children, and young people with communication disabilities in particular have, unfortunately, been excluded from research due to the challenges involved in gathering their views (Bailey, Boddy, Briscoe et al, 2015; Powrie, Kolehmainen, Turpin et al 2015).

Therefore, the research questions investigated in this study were:

1. What is the meaning of leisure for children and young people with complex disabilities that significantly limit their physical and communicative ability?
2. How do these children and young people experience leisure?

Method:

The search for meaning at the heart of this study assumes that meaning comes from within people through their interactions with the world in which they live (Patton, 2002). The exploration and creation of meaning by describing and discussing lived experience is the purpose of phenomenology (van Manen, 1990). Specifically, this study used Hermeneutic Phenomenology as its research design, one approach to phenomenology.

Ethical approval was granted in 2011 from both the local National Health Service Research Ethics Committee in the United Kingdom and the Australian University overseeing the study. Verbal consent was gained from all participants. Written consent was not physically possible due to mobility restrictions. Written consent from parents was also provided where appropriate, depending on age and capacity.

Data was sought directly from CYP about their experience of leisure. Hermeneutic studies seek in-depth, rich information from an appropriate few, rather than a fully representative, randomised sample (O'Reilly and Parker, 2012), whilst still allowing for sufficient richness of the data. Purposive sampling identified six participants who ranged in age from 9-19 at the beginning of the interview process, with an even mix of males and females. All participants were of white British ethnicity, and all had a primary diagnosis of cerebral palsy. Tables 1 and 2 provide further information about the participants and their families.

Table 1: Characteristics of Participants

Participant*	Age	Sex	Ethnicity	Diagnosis	Classification			
					GMFCS ²	MACS ³	CFCS ⁴	EDACS ⁵
Louise	16	F	White British	Dystonic CP ¹	5	5	2 (switch scan VOCA ⁶)	3 TD ⁷
Peter	19	M	White British	Dystonic CP	5	5	2 (eye-gaze VOCA)	5 TD
Matthew	15	M	White British	Hypertonic CP	5	5	3 (speech)	5 TD
Heather	13	F	White British	Dystonic CP	5	5	2 (eye-gaze VOCA)	5 TD
Sapphire	9	F	White British	Dystonic CP	4	4	2 (eye-gaze VOCA)	5 TD
Alex	18	M	White British	Hypertonic CP, epilepsy	4	4	3 (signing, gesture)	3 RA ⁸

* Pseudonyms have been used

¹ cerebral palsy; ²Gross Motor Function Classification System; ³ Manual Ability Classification System;

⁴ Communication Function Classification System; ⁵ Eating and Drinking Ability Classification System; ⁶

Voice Output Communication Aid; ⁷ totally dependent; ⁸ requires assistance

Table 2: Context of Participants

Participant	Family structure	Contact with other parent	Position in family	Siblings at home	Other siblings	School
Louise	Single mother	None	Youngest	1 older brother	No	Mainstream school
Peter	Married parents	NA	Oldest	2 – Younger brother and sister	No	Supported unit in mainstream
Matthew	Married parents	NA	Youngest	1 older brother	2 brothers, 1 sister	Mainstream school
Heather	Single mother	Weekly	Oldest	1 younger brother	No	Mainstream school
Sapphire	Single mother	Weekly	Youngest	0	2 older half brothers	Special school
Alex	Married parents	NA	Oldest	1 younger sister	No	Special school

Participants were interviewed three times over approximately six months. A semi-structured interview format based on open-ended questions was used, supported by photo elicitation, Talking Mats and direct observation. The interviews were tailored to suit the communication needs of each participant. Interviews were recorded, and statements made via communication aids were written verbatim and repeated out loud by the interviewer for the recording. Talking Mats were photographed.

Data analysis was undertaken in two ways. First, individual narratives were generated from the interview data. Narratives included direct quotes from participants along with contextualising comments made by the interviewer. The narratives were member-checked with participants to check the interviewer had understood their intended meanings, to ensure trustworthiness of the narratives (Finlay, 2011).

Second, a cross-case analysis of the complete data set was undertaken to identify similar and different experiences across cases. The results of this analysis were further informed by published autobiographies written by people with similar disabilities to enhance understanding of the meaning of the results. Data analysis was iterative and multi-directional over multiple stages. Field notes, memos and group discussions with advisors, and ongoing communication with one participant,

were used as reflective tools to identify assumptions, and to provide challenges and critical review of emerging themes.

Results/Findings

Participants

Detailed narratives were produced for each participant, exploring their leisure experiences and meanings. The personality of each individual interacted with his or her circumstances to create a unique set of leisure preferences that informed and influenced their leisure experiences. The narratives are not reported in this paper, but excerpts are included within the cross-case analysis and a summary of the activities that felt like leisure to participants and their definitions of leisure are provided in Table 3. Statements in bold are direct quotes from participants. Non-bold quotes are extracts from the member-checked summaries.

Table 3: Definitions and examples of leisure for participants

<i>Participant</i>	<i>Leisure definition</i>	<i>Leisure activities</i>
Louise	“ [Leisure] is massively important as it helps me relax and it helps me be myself. ”	Being with friends, social media, outings, computer games, reading, attending “Boyzone” concerts and dancing
Peter	Leisure is “ relaxing ” and feels “ enjoyable ”	Horror movies with friends, watching TV, listening to heavy rock music, writing song lyrics, attending gigs, moshing at concerts, outings, travelling
Matthew	Leisure “ helps me relax. ”	Being with friends, watching Youtube videos in his room, listening to music, visiting his favourite restaurant, social media, organising events and entertaining others
Heather	Leisure is “ things I do in my spare time ” to feel “ chilled out ”.	Chatting and laughing with others, social media, computer games, watching TV, web browsing, arts and crafts, colouring

		in, listening to music, dancing, swimming, shopping
Sapphire	Leisure feels “ good ” and makes her “ happy ”	Thrill rides, swimming, watching and playing football, dancing, eating out, playing with friends and brothers, sleepovers, social media, gaming
Alex	Leisure feels “ good ”, “ exciting ” and makes him “ laugh ”	Watching and playing football, following his favourite teams, outings, listening to music, air shows, thrill rides, dressing up, swimming, dancing, going to the pub

Cross-Case Analysis: The Tree of Leisure

Cross-case analysis revealed that the meaning of leisure is present both in the anticipation prior to and in the moment of the experience, but also in the outcomes created through leisure experiences. Three **essential features** were core to the experience of leisure, including feeling control over their participation, being engrossed and enjoying it. Leisure was experienced in the context of a specific activity and was impacted by the wider environment. Four **key meanings** of leisure experiences were identified: escape, exploration, expression and exchange. These features and meanings have been arranged using a metaphor of a tree to illustrate the experience of leisure (Figure 1).

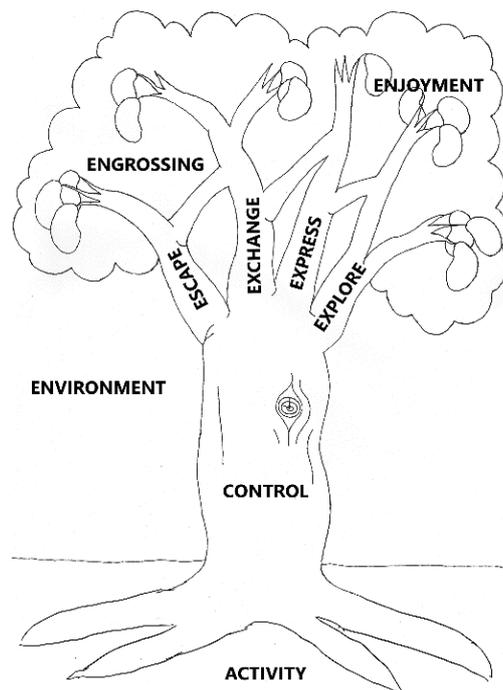


Figure 1: “The Tree of Leisure”

The tree itself represents the personal experience of leisure of an individual. The tree of leisure is grounded in an activity context and surrounded by the broader environment, both of which affect the quality of the experience of leisure. The fruit of leisure is enjoyment. The nature of the enjoyment varied depending on the activity, which, using the tree metaphor, resulted in the different flavoured fruit of leisure such as excitement, relaxation or joy, as reflected in the definitions given by participants. The canopy within which the fruit grows and is nourished represents the engrossing nature of the experience of leisure. Activities were experienced as leisure if they were engrossing, absorbing the attention of the individual, so they lost track of time and of themselves.

Sapphire: An activity wasn't leisure if it was boring or felt like work. Time went more slowly when she felt **“bored”** such as during maths, but went quickly when she was doing something fun like **“football”**

The trunk is the core of the tree and represents control. Participants needed to feel in control and have choice for an activity to feel like leisure.

Peter: It was important that assistants **“ask me”**, so that he was in control and could make his own leisure choices.

From the trunk grow the four branches of the tree of leisure: exploration, escape, expression and exchange. These branches are intrinsically linked – while they are distinct, they are not completely independent of each other.

Escaping, Relaxing and Releasing

Leisure was experienced when participants felt a sense of escape and relaxation, where worries were laid aside and participants were free to be themselves without demands from others.

Heather: Heather defined leisure as **“things I do in my spare time” to feel “chilled out”**.

Solitary leisure activities provided an escape by allowing time away from others and to focus on their own preferences. By having space to be themselves, they didn't need to focus on how they were appearing or what others were thinking.

Peter: Peter sought leisure by escaping into the sanctuary of his bedroom where he could **“get away”**, have a break from other people and **“clear my head”**.

Leisure helped to release emotions and pent-up tensions, distract from bothersome thoughts and events and lift the spirits by improving mood. Leisure as escape was actively used to pass the time and make potentially boring periods more engrossing. Louise and Matthew described using their inner world through fantasy to reclaim leisure when they felt bored, such as while waiting for others to provide care, to help time pass more quickly and enjoyably.

Matthew: To pass the time, **“I just sit around singing in my head”**.

Leisure as escapism led to feelings of relaxation, which was both a physical and an emotional state where tension was released, and mind and body felt refreshed.

Louise: **“[Leisure] is massively important as it helps me relax and it helps me be myself.”**

Exchanging, Relating and Connecting: “Just being able to spend time with them and having a laugh”

Leisure was experienced when participants felt included and valued, and where they felt a sense of exchange, contributing to, as well as receiving from, interactions. Interactions could be light and fun, with silliness and laughter. They could also be more intense, involving sharing of experiences and feelings.

Louise: **“I remember at times we were hurting from laughing so hard and that felt great. Also we were talking about things that aren’t meant for people who have light minds and that was entertaining too.”**

Spending time and communicating with others was leisure, whether during break times at school, on outings, or even via social media. Being a part of family, friends and the wider community featured frequently in the stories shared by participants. Leisure was at its most rewarding when spent with other people, especially when there was mutual appreciation and value.

Matthew loved **“going out to my favourite restaurant”** because **“I’ve got loads of friends who work there”** and **“they come up and talk to me, even if they are really busy.”**

Most participants enjoyed leisure with their families, and valued opportunities for togetherness with at least some members of the family.

Alex: He liked to be with his **“uncle”** and the other males when the family were having a get together BBQ. He liked being in charge of the fire.”

Hanging out with others could act as a distraction from unpleasant thoughts or events and help overcome negative emotions. Most activities were enhanced by doing them together, and just being with others was often enough in itself to constitute pleasurable leisure.

Heather: It felt like leisure when **“I went for a walk with my mate”**, and **“I joined in the conversation”** and **“it was just a [chance to] catch up”**. It was the chat that felt like leisure, and the walk was where the chat happened.

Break-times at school were viewed as leisure when there were opportunities to be with peers. Conversely, breaks became an ordeal to get through when participants were deprived of the company of friends.

Louise: **“Outside of class, I possessed limited interaction with my peers and that caused me to feel isolated from the rest of the school.”**

Time with peers was reduced for many participants by the structure of school regimes around care-giving and assistance. Attitudes to school were heavily influenced by their negative break time experiences. Some participants were closely supervised at school, so even when they were with their peers, they felt under the gaze of adults. It is likely that their peers felt similarly watched over when playing with or near them, which is unlikely to have enhanced the social opportunities of participants.

Peter: Assistants were **“very strict”** at **“primary school”**. There was a sense of assistants **“watching over”** Peter and being over-protective, which led to Peter feeling constantly under the gaze of adults. This made it hard to relax, and harder to do things, making activities feel less like leisure.

Expressing and Creating

Leisure was experienced when participants were able to convey aspects of themselves to the outside world, as well as to themselves. The participants experienced pleasure in the act of creation, and the process of engaging in imagination, expression and self-discovery.

Peter: He spent hours working on writing song lyrics as a form of self-expression as it **“lets what’s in my mind out”**.

Special interests and special occasions emerged as important opportunities to signify identity to others. Special interests gave participants pleasure, allowed expression, provided opportunities for relating and formed part of their identity. Clothing and other visual identifiers were used to signify their interests – the football

supporters, movie buffs and music fans were all observed to express their interests through dress, bedroom décor and social media.

“Alex loved going to air shows with his family and meeting **“pilots”**. Once he was wearing his Hungarian Air Force T-shirt, and the Hungarian pilots wanted to have their photo taken with him, which made Alex very happy.”

The intensive nature of expressive leisure activities helped them to build their capacity to concentrate and overcome challenges, which may have developmental implications on their readiness for adulthood.

Matthew organised talented students from his school to perform at the **“open garden”** event. He reported that this involved work **“but it isn’t like school work ... because [organising the entertainment] is fun and the other one is boring.”**

For some, sharing the results of their creativity with others gave life to their expression, an example of where the branches of the tree of leisure intertwine.

Matthew: **I feel happy that everyone gets to see and hear the talent [from my school]”**.

Parties could be avenues to build relationships with others, by allowing them to be seen differently.

“Alex enjoyed dressing up as different people for fun and for parties. He dressed up as **“Elvis”**, with a wig and a **“guitar”** which was **“exciting”**.

Exploring, Experiencing and Achieving

Leisure was experienced when participants felt excited and exhilarated through exploring and learning about the world around them and stretching themselves to new achievements. The young people explored their personal boundaries through experiencing sensations and emotions, testing bravery and resilience, developing new skills, competing with others and rising to new challenges.

Sapphire: Sapphire felt “**excited**” on rides. She wasn’t scared at all. She really likes the feeling of going fast, up and down and round and round, as well as the drop rides.”

Opportunities to move freely were important to participants, and dancing and swimming were almost universal in their appeal. Louise spoke of dancing so vigorously that she nearly slid out of her chair.

Heather: When the people and the music are right, and the dancing feels good, it is “**exciting**” and makes Heather feel “**happy**”.

Matthew, Sapphire and Alex elaborated on their swimming experiences, indicating that moving freely, kicking and floating in the water were pleasurable and relaxing.

Alex: He liked “**swimming**” in the sea, if the water was “**warm**”. He liked “**waves**” especially in the wave machine pools at water parks.

Sapphire: Floating in the water during “**swimming**”, dancing to music like “**One Direction**” and “**Justin Bieber**” and “**football**” were “**fun**” and made her excited and happy by providing her with opportunities for free movement.

Through experiencing and interacting with the world, participants learned more about themselves and their community, and made a statement about their place in it. Exploratory leisure provided opportunities for casual leisure experiences that may become more serious over time. The wider world gave them new sights, sounds and physical sensations, providing a sense of excitement, connection and belonging.

Discussion and implications:

Understanding what makes a meaningful leisure experience from the perspective of young people guides us to the elements to consider in supporting leisure participation. The study found that leisure leads to outcomes that last beyond the experience of leisure. These include restoration through relaxation and stress reduction, protection through enhanced resilience and coping, construction of self-

efficacy and empowerment, reflection on and development of identity and increased connection with others and the world around them. A balance of leisure experiences appears to be important to ensure access to the full array of leisure outcomes.

The differences between these young people and the general population related to the mechanics of leisure, rather than the experience or meanings of leisure. Their requirement for assistance to engage in activities that their peers do independently and the environmental challenges to leisure participation they faced presented the biggest differences.

Implications for Occupational Therapy Practice

Occupational therapists have often used leisure as a therapeutic tool to improve functional performance, rather than as the end goal of intervention (Lynch, Prellwitz, Schulze et al, 2018). A combination of time and resource constraints has led to prioritisation of self-care and productivity at the expense of leisure (Chen and Chippendale, 2018). The findings of our study elucidate the importance of leisure to subjective wellbeing and ongoing development, providing clear examples of the power of leisure to enhance skills, develop relationships and prepare young people for adult life. The “tree of leisure” metaphor outlines the leisure elements to be considered when addressing an individual’s leisure needs. Facilitating successful leisure experiences could go a long way to reaching many of the goals occupational therapists currently feel pressured to prioritise, whilst naturally achieving other meaningful outcomes and contributing directly to immediate wellbeing. Leisure experiences could be improved by broadening the leisure opportunities available to young people with disabilities, increasing social contact with peers, improving the quality of assistance provided during leisure, encouraging young people to self-advocate and supporting them to engage in physical movement for pleasure.

Promoting the importance of leisure

Occupational therapists can enhance leisure experiences for CYP with complex disabilities by addressing structural issues in the environment that impact on the occupational rights of these young people (Hammell, 2015). The supports and barriers presented by the environment may be easier to modify than the functional difficulties experienced by young people with complex physical disabilities (Anaby et

al., 2014). For example, break-times are often viewed as a lower priority than the need for assistance for personal care tasks and attendance in class, and access to play and leisure are often not valued (Sterman, Naughton, Bundy et al, 2018). Supporting school staff to re-evaluate these priorities and understand the importance of leisure time and what it offers to young people may help to unblock institutional processes and result in change across the system. Universal approaches that focus on whole school systems will have a much broader impact than working at the individual level, but require occupational therapists, and the systems they work within, to view such structural approaches as a legitimate intervention (Espín-Tello and Colver, 2017). Research directed at how to influence practitioner beliefs and priorities around targets for and methods of interventions may help us to understand how best to prioritise and address leisure.

Broadening opportunities and experiences of leisure

Occupational therapists can work at both the structural level and the individual level to ensure young people have access to diverse leisure experiences to promote leisure balance. Occupational therapists can take an active role in advocating on behalf of, and alongside, young people with disabilities, to promote their inclusion in community activities. At a universal level, community offers of leisure experiences can be affected by the confidence and competence of leisure staff, which can be improved through consultation and training (King, Curran and McPherson, 2013). Direct involvement of therapists alongside leisure providers can reassure families that their child will receive appropriate support and make them more likely to access programmes (Fernandez, Ziviani, Cuskelly et al, 2018).

At an individual level, therapists can take the time to explore preferences and experiences and encourage young people to try new things that may be of interest to them. This could include supporting young people to search for potential activities and resolving logistical issues such as transport and ticket purchasing (Imms, Mathews, Richmond et al, 2016). Starting activities for the first time can be daunting for anyone, and particularly for young people with complex disabilities, so ensuring that they are as well prepared for new experiences as possible and providing advocacy and support can facilitate their entry to new opportunities.

Improving control over leisure through self-advocacy and quality assistance

One of the unique challenges faced by young people with complex disabilities is the need to direct others to assist them. The need for assistance itself did not detract from leisure, but the nature of the assistance and the presence of the assistant had a significant impact on how leisure was experienced. Leisure would appear to be a constructive environment to support young people to build their confidence with self-advocacy, especially around their assistance needs. To do this effectively, they need to have a strong sense of self, and of their preferences for how they want their leisure to occur. Several of the participants lacked confidence in telling their paid assistants how they wanted to be helped. Managing difficulties with staff can be very challenging for young adults with disabilities (Mitchell, Beresford, Brooks et al, 2017).

Young people could be involved in the training of their personal assistants by consulting actively with them about how they prefer to be helped. Young people appreciate opportunities to work closely with teachers and assistants to determine their support needs, and solving problems together in this way builds trust (Asbjornslett and Hemmingsson, 2008). By explicitly engaging the young people themselves in training and inducting staff they are being given a clear message about their role and identity as the controller of the situation rather than recipient of care, conferring status and power to the young people.

Increasing social contact with peers to promote exchange leisure

Peer contact both in and outside of school was limited for most participants, echoing the evidence that young people with disabilities have reduced access to peers, fewer friends, and lower quality of life related to social participation (Colver et al., 2015).

Supporting the development of friendships through creation of opportunities for social participation from early in life should be a priority area for research and support for young people (Rossetti and Keenan, 2017). Community integration interventions are effective in supporting inclusion, especially where there is a focus on friendships alongside leisure, by including typically developing peers with similar activity preferences (Andrews, Falkmer and Girdler, 2015). Socialising opportunities at school can be maximised through peer network interventions, where a facilitator supports a group of students with mutual interests to engage in enjoyable activities and plan future ones (Carter, 2018).

Participants were assumed to need adult support throughout school breaks. Assistants acted as gatekeepers to the type and quality of leisure that the participants had access to, and especially impacted on the nature of interaction with peers. There is evidence that one-to-one adult assistance can impair social interaction (Asbjornslett and Hemmingsson, 2008). With good quality training and ongoing support there are many tasks that peers would be able to complete safely, including supporting mobility. It is important to recognise that promoting friends as assistants has the potential to impact negatively on the social relationship. CYP with physical disabilities like the idea of assistance from friends, but only if that help naturally occurs as part of friendship (Rossetti and Keenan, 2017).

Siblings were effective facilitators of social leisure, providing normal growing up experiences such as rough and tumble play. They supported integration of young people with disabilities into local communities without parental attendance and appeared to provide effective modelling to peers. Supportive sibling relationships in adolescence are predictive of life satisfaction in early adulthood (Hollifield and Conger, 2015). Attending to and valuing the relationships young people with disabilities have with their siblings, and how these relate to leisure experiences, have the potential to enhance life satisfaction for both.

Supporting movement for pleasure

The participants in the study valued movement experiences as part of their leisure. Freed from the constraints of equipment and limitations, the participants delighted in throwing themselves into swimming, dancing and cycling. While the bodies of these young people may work in different ways, these experiences highlight the nature of the 'lived body' as their conduit to perceiving and experiencing the world (Park Lala and Kinsella, 2011). Valuing, promoting and enabling enjoyable physical experiences in leisure is as important to this group of young people as it is to their peers. Creating spaces where free movement is encouraged and accepted, where they can feel that their whole embodied self is valued and valuable, may be an important area for therapists to consider.

Limitations of the study and recommendations for further research

The demographics of the participant group lacked diversity. All were white British and had a diagnosis of cerebral palsy. Five out of six of the participants were

teenagers. Findings may be different with a younger age group, particularly around aspects such as the importance of identity development. Exploring experiences of those from different cultures could also help to further illuminate the phenomenon of leisure experience and meaning.

Texts were co-constructed between the participants and the researcher. Interviewing through augmentative communication necessarily occurs at a slow pace. It may be that some nuances around leisure experience were missed as a result of interviewer choices regarding what to pursue. Efforts to address inherent bias included triangulating the information by referring to previous answers and member checking.

Leisure is not universally positive in experience, nor is it universally beneficial (Layland, Hill and Nelson, 2018). The darker side of leisure experience and leisure impact were not explored in this study, but are important areas for future research.

Conclusion

Young people experience leisure during enjoyable activities when they are engrossed and in control. They seek leisure experiences that reflect their desire for escape, exploration, expression and exchange. By doing so, they experience outcomes which have restorative, protective, constructive, reflective and connective benefits. Leisure balance is individually determined, depending on each person's perspective of the right amount and variety of leisure occupations. Ultimately, leisure provides life with deeper meaning, opportunities for enjoyment, connection with others and the world around. It contributes to identity and self-efficacy and provides a way to cope with life's challenges. Supporting meaningful leisure participation should be a priority for all occupational therapists.

Key findings:

- Opportunities for escape, exploration, expression and exchange are sought through leisure
- Outcomes of leisure include restoration, protection, reflection, connection and construction of identity
- Leisure gives life meaning

What the study has added:

Leisure is a vital source of life meaning, and therefore a worthy focus of clinical time for occupational therapists wishing to enhance the wellbeing of children and young people.

References (34)

- Allard, A., Fellowes, A., Shilling, V., Janssens, A., Beresford, B., and Morris, C. (2014). Key health outcomes for children and young people with neurodisability: qualitative research with young people and parents. *BMJ Open*, 4(4). doi:10.1136/bmjopen-2013-004611
- Anaby, D., Law, M., Coster, W., and Bedell, G. (2014). The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. *Archives of Physical Medicine and Rehabilitation*, 95(5), 908.
- Andrews, J., Falkmer, M., and Girdler, S. (2015). Community participation interventions for children and adolescents with a neurodevelopmental intellectual disability: a systematic review. *Disability and Rehabilitation*, 37(10), 825-833. doi:10.3109/09638288.2014.944625
- Asbjornslett, M., and Hemmingsson, H. (2008). Participation at school as experienced by teenagers with physical disabilities. *Scandinavian Journal of Occupational Therapy*, 15(3), 153-162. doi:10.1080/11038120802022045
- Bailey, S., Boddy, K., Briscoe, S., and Morris, C. (2015). Involving disabled children and young people as partners in research: a systematic review. *Child: Care, Health and Development*, 41, 505-514. doi:10.1111/cch.12197
- Bedell, G., Coster, W., Law, M., Liljenquist, K., Kao, Y.-C., Teplicky, R., . . . Khetani, M. A. (2013). Community participation, supports, and barriers of school-age children with and without disabilities. *Archives of Physical Medicine and Rehabilitation*. doi:10.1016/j.apmr.2012.09.024
- Carter, E. W. (2018). Supporting the social lives of secondary students with severe disabilities: considerations for effective intervention. *Journal of Emotional and Behavioral Disorders*, 26(1), 52-61. doi:10.1177/1063426617739253

Chen, S.-W., and Chippendale, T. (2018). Leisure as an end, not just a means, in occupational therapy intervention. *American Journal of Occupational Therapy*, 72(4). doi:10.5014/ajot.2018.028316

Colver, A., Rapp, M., Eisemann, N., Ehlinger, V., Thyen, U., Dickinson, H. O., . . . Arnaud, C. (2015). Self-reported quality of life of adolescents with cerebral palsy: a cross-sectional and longitudinal analysis. *The Lancet*, 385(9969), 705-716. doi:10.1016/S0140-6736(14)61229-0

Dahan-Oliel, N., Shikako-Thomas, K., and Majnemer, A. (2012). Quality of life and leisure participation in children with neurodevelopmental disabilities: a thematic analysis of the literature. *Quality of Life Research*, 21(3), 427-439. doi: 10.1007/s11136-011-0063-9

Espín-Tello, S. M., and Colver, A. (2017). How available to European children and young people with cerebral palsy are features of their environment that they need? *Research in Developmental Disabilities*, 71, 1-10. doi:10.1016/j.ridd.2017.09.018

Fernandez, Y., Ziviani, J., Cuskelly, M., Colquhoun, R., and Jones, F. (2018). Participation in community leisure programs: Experiences and perspectives of children with developmental difficulties and their parents. *Leisure Sciences*, 1-21. doi:10.1080/01490400.2017.1408509

Hammell, K. W. (2015). Participation and occupation: The need for a human rights perspective. *Canadian Journal of Occupational Therapy*, 82(1), 4-5. doi:10.1177/0008417414567636

Hollifield, C. R., and Conger, K. J. (2015). The role of siblings and psychological needs in predicting life satisfaction during emerging adulthood. *Emerging Adulthood*, 3(3), 143-153. doi:10.1177/2167696814561544

Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., and Granlund, M. (2016). 'Participation': a systematic review of language, definitions, and

constructs used in intervention research with children with disabilities.

Developmental Medicine & Child Neurology, 58(1), 29-38.

doi:10.1111/dmcn.12932

Imms, C., Mathews, S., Richmond, K., Law, M., and Ullenhag, A. (2016). Optimising leisure participation: a pilot intervention study for adolescents with physical impairments. *Disability and Rehabilitation*, 38(10), 963-971.

doi:10.3109/09638288.2015.1068876

King, G., Curran, C., and McPherson, A. (2013). A four-part ecological model of community-focused therapeutic recreation and life skills services for children and youth with disabilities. *Child: care, health and development*, 39(3), 325-336. doi:10.1111/j.1365-2214.2012.01390.x

Lapa, T. Y. (2013). Life satisfaction, leisure satisfaction and perceived freedom of park recreation participants. *Procedia - Social and Behavioral Sciences*, 93, 1985-1993. doi:10.1016/j.sbspro.2013.10.153

Layland, E. K., Hill, B. J., and Nelson, L. J. (2018). Freedom to explore the self: How emerging adults use leisure to develop identity. *The Journal of Positive Psychology*, 13(1), 78-91. doi:10.1080/17439760.2017.1374440

Lynch, H., Prellwitz, M., Schulze, C., and Moore, A. H. (2018). The state of play in children's occupational therapy: A comparison between Ireland, Sweden and Switzerland. *British Journal of Occupational Therapy*, 81(1), 42-50.

doi:10.1177/0308022617733256

Mitchell, W., Beresford, B., Brooks, J., Moran, N., and Glendinning, C. (2017).

Taking on choice and control in personal care and support: The experiences of physically disabled young adults. *Journal of Social Work*, 17(4), 413-433.

doi:10.1177/1468017316644700

Mundhenke, L., Hermansson, L., and Sjoqvist Natterlund, B. (2010). Experiences of Swedish children with disabilities: activities and social support in daily life.

Scandinavian Journal of Occupational Therapy, 17(2), 130-139.

doi:10.1080/11038120903114386

O'Reilly, M., and Parker, N. (2012). 'Unsatisfactory Saturation': a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, 13(2), 190-197. doi:10.1177/1468794112446106

Park Lala, A., and Kinsella, E. A. (2011). Phenomenology and the study of human occupation. *Journal of Occupational Science*, 18(3), 195-209.

doi:10.1080/14427591.2011.581629

Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods* (3 ed.).

Thousand Oaks: Sage Publications.

Piškur, B., Beurskens, A., Jongmans, M., Ketelaar, M., and Smeets, R. (2015). What do parents need to enhance participation of their school-aged child with a physical disability? A cross-sectional study in the Netherlands. *Child: care, health and development*, 41(1), 84-92. doi:10.1111/cch.12145

Powrie, B., Kolehmainen, N., Turpin, M., Ziviani, J., and Copley, J. (2015). The meaning of leisure for children and young people with physical disabilities: a systematic evidence synthesis. *Developmental Medicine & Child Neurology*, 57(11), 993-1010. doi:10.1111/dmcn.12788

Roskam, I., Meunier, J.-C., and Stievenart, M. (2015). From Parents to Siblings and Peers. *SAGE Open*, 5(4). doi:10.1177/2158244015611455

Rossetti, Z., and Keenan, J. (2017). The nature of friendship between students with and without severe disabilities. *Remedial and Special Education*, 195-210. doi:10.1177/0741932517703713

Schreuer, N., Sachs, D., and Rosenblum, S. (2014). Participation in leisure activities: Differences between children with and without physical disabilities. *Research*

in Developmental Disabilities, 35(1), 223-233.
doi:<http://dx.doi.org/10.1016/j.ridd.2013.10.001>

Sterman, J. J., Naughton, G. A., Bundy, A. C., Froude, E., and Villeneuve, M. A. (2018). Is play a choice? Application of the capabilities approach to children with disabilities on the school playground. *International Journal of Inclusive Education*, 1-18. doi:10.1080/13603116.2018.1472819

Suto, M. (1998). Leisure in occupational therapy. *Canadian Journal of Occupational Therapy*, 65(5), 271-278. doi:10.1177/000841749806500504

van Manen, M. (1990). *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. New York: State University of New York.

Woodgate, R. L., Edwards, M., and Ripat, J. (2012). How families of children with complex care needs participate in everyday life. *Social Science & Medicine*, 75(10), 1912-1920. doi:10.1016/j.socscimed.2012.07.037