Fostering Quality Participation for Children with Intellectual and Developmental Disabilities

Evidence-informed guidance is needed to appropriately support and effectively foster quality participation – defined as satisfying, enjoyable, and meaningful involvement – for children with intellectual and developmental disabilities (IDD). Quality participation is the result of repeated and sustained quality experience. Six building blocks contribute to a quality experience: autonomy, belonging, challenge, engagement, mastery, and meaning.

**AUTONOMY**
Having independence, choice, control

**BELONGINGNESS**
Feeling included, accepted, respected, part of the group

**CHALLENGE**
Feeling appropriately tested

**ENGAGEMENT**
Being in-the-moment, focused, absorbed, fascinated

**MASTERY**
Feeling a sense of achievement, accomplishment, competence

**MEANING**
Contributing toward obtaining a personal or socially meaningful goal; feeling a sense of responsibility to others
Although researchers have begun to explore quality participation among individuals with disabilities\(^1\)-\(^3\), additional research is needed to expand our understanding of quality participation for children with IDD. Consequently, the Canadian Disability Participation Project (CDPP) set out to broaden this understanding by conducting a systematic scoping review\(^4\). A systematic scoping review identifies all relevant research about a particular topic from several different sources of evidence, such as: published literature, grey literature (non-peer reviewed), and expert consultation. Data from the research is then extracted, and key concepts are grouped into themes. Our CDPP review, led by Natasha Bruno and completed in 2020, sought to explore the participation experiences of children with IDD aged 2-12 years across leisure, education and rehabilitation areas\(^5\).

From this review, we determined the building blocks of quality experience are relevant to children with IDD. We also identified and synthesized a comprehensive list of practical strategies underpinning the building blocks and outcomes associated with quality participation.

**Defining the Problem**

Previous research has demonstrated that the participation needs for children with IDD are often neglected, leading to various physical, social, communication, and policy barriers to participation\(^6\). Yet, the importance of participation is well established; participation is constituted as a human right\(^6\) and quality participation is a valued life outcome for children with IDD. Children with IDD and their families are not only concerned with having access to participation opportunities, but also the quality of their experience while participating\(^8\).

Programs for children with IDD should strive to actively consider how to incorporate strategies to facilitate these valued building blocks associated with quality experiences and positive participatory outcomes.

**Building Quality Experiences and Positive Outcomes**

Our review identified 35 studies, including the experiences of 431 children with IDD and 1271 proxies (e.g., parents). All six building blocks were identified as relevant to fostering quality experience among children with IDD. All of the potential positive outcomes associated with quality participation that were identified in our review, include:

- Empowerment
- Independence
- Friendship
- Enjoyment
- Confidence
- Skills (i.e., advocacy, motor, interpersonal, and life)
- Psychological benefits (i.e., emotional growth; enhanced well-being; improved concentration, mood and behaviour; motivation; and life satisfaction)
- Inclusion

These outcomes highlight the importance of quality programming for children with IDD. The following table describes the thirty identified facilitative strategies that can be used by program providers to foster the building blocks for their participants. The strategies are categorized by program environment.
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<th>Environment</th>
<th>Facilitative Strategies for Program Providers</th>
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| **Physical Environment** | - Environments should be accessible and/or modified to accommodate individualized needs  
  - A variety of appropriate equipment and aids should be readily available  
  - Environments should be designed to make the children feel safe and protected  
  - Programs should be located conveniently and occur at suitable times  
| **Program Environment** | - Environments should support children with differing abilities, age, skills, and disability status  
  - Opportunities should be low cost  
  - Instructors should encourage children to set self-selected goals to create meaningfulness  
  - Activities and programs should be tailored to individuals’ needs and differing pace for developing skills  
  - Low stimulus environments are recommended to be considerate of sensory sensitivities  
  - Time for free play should be incorporated to facilitate peer interaction and participating in activities the children enjoy  
  - Programs should offer a range of options for activities according participant needs/strengths  
  - Routines in the programming can create a sense of security and understanding for the children  
  - Activities should be low-risk and limit the possibility for injury  
  - Programs should be structured with a clear purpose while remaining flexible to goals/interests |
| **Social Environment – Instructor** | - Instructors should be able to manage behavioural difficulties/challenges in an appropriate manner  
  - Children should be consulted and encouraged to offer their opinions  
  - Instructors should encourage open communication from the children  
  - Instructors should be flexible, prepared, knowledgeable and innovative  
  - Instructors should support self-monitoring so the children can track their improvement  
  - Instructors should validate the children’s contributions through methods like awards, prizes, verbal praise, etc.  
  - Instructors should have good interpersonal skills like being understanding, accepting, empathetic, and welcoming |
| **Social Environment – Peer** | - Group environments should foster support, teamwork, social interaction, a sense of belonging, and group identity among peers  
  - Participants should have opportunity of mentor others or seek personal mentors to establish relationships with |
| **Social Environment – Family** | - Collaboration between instructors and family members is encouraging to enable knowledge sharing and an understanding partnership  
  - Instructors should be comfortable educating family members on how they can better support activities at home to ensure successful experiences  
  - Programs should offer opportunity for family members to support their children’s participation by integrating them into activities and the community |
| **Social Environment – General** | - Children should be able to participate without being subjected to scrutiny or humiliation  
  - Children should perceive positive attitudes towards participation from all involved  
  - Environments should support all status’ of disability equitably  
  - All children should have a welcoming experience with the opportunity to pursue unique pathways (forms of participation, competition levels) through the program |
In Summary

Our systematic scoping review identified evidence that describes valued building blocks of quality experience for children with IDDs. These building blocks can be fostered through a combination of the identified facilitative strategies and have been shown to result in subsequent positive participatory outcomes such as empowerment, friendship, inclusion. We recommend program providers, for current and future participation initiatives for children with IDDs, consider integrating our findings into their programming to ensure children are participating in quality and meaningful leisure, educational, and rehabilitative experiences.9,10

References


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