Measuring Barriers and Accommodations to Social Inclusion and Participation of Children with an Intellectual or Developmental Disability

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PRESENTATION PLAN

RATIONALE FOR DEVELOPING A NEW MEASURE OF SOCIAL PARTICIPATION

OUR BARRIERS AND ACCOMMODATIONS QUESTIONNAIRE

PRELIMINARY RESULTS FROM OUR SURVEY IN WESTERN QUEBEC
CONTEXT

• Rehabilitation Centre for Intellectual and Developmental Disability in Western Quebec and Université du Québec en Outaouais partnership

• Planning, programming and research objectives:
  • Building more inclusive communities by promoting social participation

• Example:
  • Intensive Early Intervention Programs provided in inclusive daycare settings
• People with intellectual disabilities are *present* in the community...

• But are they *participating* fully in society?

• How are *children* with intellectual or developmental disabilities expected to take part in their community as *citizens*?

• What *barriers* do they face?

• What *facilitates* social participation when they are included?
SOCIAL PARTICIPATION MEASURES

- Participation Scale (Van Brakel et al, 2006)
- Impact on Participation and Autonomy (IPA) (Cardol, De Jong, & Ward, 2002)
- LIFE-H (Noreau, Lepage, Boissière, Picard, Fougeyrollas, et al., 2007)
- Lifestyle Assessment Questionnaire (LAQ-G) (Jessen, Colver, Mackie, & Jarvis, 2003)
- WHO Disability Assessment Schedule (WHODAS 2.0) (WHO, 2010)

✓ Developed for adults
✓ Built with physical disability in mind
✓ Focus on autonomy rather than inclusion and social participation
WHODAS 2.0

Domains

1. Cognition
2. Mobility
3. Self-Care
4. Life Activities
   ▪ Household Activities
   ▪ Work or School Activities
5. Getting Along with People
6. Participation
In the past 30 days, how much difficulty did you have...

1. Cognition
   ... Concentrating on doing something for ten minutes?

2. Mobility
   ... Standing up from sitting down?

3. Self-Care
   ... Washing your whole body?
WHODAS 2.0

Because of your health condition, in the past 30 days, how much difficulty did you have...

4. Life Activities
   ... Getting all the [household/ school] work done that you needed to do?
   Did you earn less money as the result of a health condition?
   In the past 30 days, how much difficulty did you have...

5. Getting along with people
   ... Making new friends?
In the past 30 days:

6. Participation

... How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?

... How much has your health condition been a drain on the financial resources of you or your family?
OUR BARRIERS AND ACCOMMODATIONS QUESTIONNAIRE

• Inspired by the Barriers and Accommodations Index (BAI) published by Zubrow, Rioux and collaborators (2009)

• Based on Statistics Canada’s 2001 Participation and Activity Limitation Survey (PALS)

Additions

✓ Children under 15

✓ Social Settings:
  ✓ Daycare
  ✓ School
  ✓ Home
  ✓ After school care

✓ Community
  ✓ Sports and Leisure
  ✓ Day camp
  ✓ Family outings
BARRIERS AND ACCOMMODATIONS INDEX

- Technical Aids
- Community Attitudes
- Personal Beliefs
- Personal and Community Attitudes
- Personal Services
- Aids and Personal Services
- Personal and Community Services
- Aids and Personal Services
- Environment
- Financial Burden
- Structural
- Transportation
- School and Workplace
- Environment
- Medication

(Rioux, Zubrow, Stutt, Bunch, Miller, 2003; Zubrow, Rioux, Spielman, Dinca-Panaitescu, Kunkel, & Marsolais, 2009)
Did you ( . . . . ) need
(a) note takers or readers?

(PALS 2001 – Adult – D12AD)
Did you (......) require (a) accessible classrooms?

(PALS 2001 – Adult – D10AB)
What prevented you (...) from travelling locally by car?

(PALS 2001 – Adult – F15A)
Do you believe that your current employer or any potential employer would be likely to consider you disadvantaged in employment because of your condition?

(PALS 2001 – Adulte – E48)
In the past 12 months, did you ever use your medication or drugs less often than you were supposed to, because of the cost?

(PALS 2001 – Adult – B122)
Why not use PALS data?

- Sampling problems:
  - Diagnoses of intellectual disability imprecise
  - Too few under 15 with ID
    - Not representative (less than 5%)

Why not use PALS questions?

- Over representation of barriers
- Over representation of certain categories of barriers
- Under representation of children’s social settings
Which of the following conditions enabled (...) to take part in these activities? I will read you a list. Please answer yes or no to each question.

<table>
<thead>
<tr>
<th>Condition</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>People were welcoming.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You found it important that your child took part in these activities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The staff was aware of your child’s condition and received the necessary information and support.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive care and attention resources have been added.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The activities took place with young people that (he/she) knows or with family members.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The activities took place close to your home.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The activities were funded.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The transportation required for your child’s condition was available.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The activities and the material were adapted to your child’s condition.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The physical environment was safe and adapted to (...)’s condition (e.g., noise or light levels have been modified, access ramps, automatic door openers, hoists, and accessible washrooms).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
(Rioux, Zubrow, Stutt, Bunch, Miller, 2003; Zubrow, Rioux, Spielman, Dinca-Panaitescu, Kunkel, & Marsolais, 2009)
<table>
<thead>
<tr>
<th>SAMPLE BARRIERS QUESTION</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Has (....) been prevented from taking part (in certain organized activities) because...</strong></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>The activities did not meet with your interests.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People were not very welcoming.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The required supportive care and attention resources were not available.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The activities were not available close to your home.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The cost was too high.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The transportation required for your child’s condition was not available.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The activities and the material were not adapted to your child’s condition.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The physical environment was not safe and adapted to (....)’s condition (e.g., noise or light levels were not modified, no access ramps, automatic door openers, hoists, or accessible washrooms).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Methods

Participants

- 230 parents were contacted by RC in Western Quebec
- **50 parents** (43 mothers; 7 fathers) agreed to telephone interview (40-60 minutes)

Children from sample

- 16 preschoolers (0-5 yrs)
- 24 school aged (6-14 yrs);
- 17 in daycare
- 31 in school
- 2 at home
- Family
  - 36 living with both parents
  - 12 in single parent homes
  - 2 in foster care.
RESULTS – ORGANIZED SPORTS AND LEISURE

- Children with IDD (n = 42)
- Children with IDD and motor impairment (n = 7)

Bar chart showing participation in different activities:
- Sports with a Coach or Instructor
- Music or Art Lessons
- Groups or Community Programs

Legend:
- Children with IDD (n = 42) in purple
- Children with IDD and motor impairment (n = 7) in light purple
RESULTS – FREE SPORTS AND LEISURE

- Free Sports
- Park and Water Games
- Library
- Cinema or Theatre

<table>
<thead>
<tr>
<th>Activity</th>
<th>Children with IDD (n = 42)</th>
<th>Children with IDD and motor impairment (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Free Sports</td>
<td>90</td>
<td>100</td>
</tr>
<tr>
<td>Park and Water Games</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Library</td>
<td>60</td>
<td>70</td>
</tr>
<tr>
<td>Cinema or Theatre</td>
<td>80</td>
<td>80</td>
</tr>
</tbody>
</table>

Children with IDD (n = 42)
Children with IDD and motor impairment (n = 7)
RESULTS – Organized Sports and Leisure

Comparison
Children with IDD (n = 42) and Children with IDD and motor impairment (n = 7)

Those who PARTICIPATE report the following ACCOMMODATIONS

- Parents found it important (25/25; 2/2)
- People were welcoming (24/25; 2/2)
- Transportation was available (20/25; 2/2)
- Staff was informed and supported (19/25; 2/2)
- Environment was safe and adapted (18/25; 2/2)
- Activities and the material were adapted (16/25; 2/2).

Those who did NOT report the following BARRIERS

- Required accompaniment and support not available (15/20; 3/4)
- Activities and material were not adapted (12/20; 4/4)
- Environment not safe, not adapted (4/20; 3/4).
RESULTS – Unstructured Sports and Leisure

Those who PARTICIPATE report the following **ACCOMMODATIONS**

- Parents found it *important* *(40/41; 6/6)*
- People were *welcoming* *(37/40; 6/6)*
- *Transportation* was available *(33/41; 6/6)*
- *Environment* was *safe* and adapted *(27/39; 4/6)*
- *Activities* and the *material* were adapted *(27/40; 4/6)*.

Those who did NOT report the following **BARRIERS**

- Required *accompaniment and support* not available *(2/9; 1/2)*
- *Activities* and *material* were *not* adapted *(5/6; 1/1)*
- *Environment* not safe, *not* adapted *(5/11; 0/1).*
Facilitators of children’s inclusion and social participation

- **Attitudes and Beliefs**
  - Parents believe it’s important
  - People are welcoming
  - Staff is informed, trained and supported

- Parents provide *transportation*

- *Adaptation* or *universal access* of physical environnement, activities and material
Discussion

Barriers to children’s inclusion and social participation

- Lack of *Personal Services*
- Lack of Accessible *Environment* and Material
Discussion

• Few differences between IDD children with or without motor impairment (except organized sports)
  ✓ Also true of children with motor impairment without IDD

• No comparison to matched children w/o IDD:
  ✓ What is the norm?

• Perhaps greater correlation with parental education and revenue
Conclusion

• New measure
• Focus on social inclusion and participation
• Accommodations and facilitators (not only barriers)
• For Children
• With Intellectual Disability

• How does it evolve over time?
• How does it compare with general population of children?
• Future analyses will compare
  ✓ Preschoolers vs school age vs teens
  ✓ Intellectual Disabilities vs Autistic Spectrum Disorders
  ✓ Rural vs urban areas