Promoting parent professional partnerships for inclusion: Perspectives of parents, professionals and students.

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Who are we?

HELPs Inc: Health Education and Learning Partnerships Promoting Inclusion needs of young children with developmental delays or disabilities (DD) as they make the transition into elementary school.

CIHR-funded Emerging Interprofessional Team
• 5 universities
• 3 provinces: Ontario, Québec, and Nova Scotia
Interprofessional Team

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Overall Project Objectives

To describe:

- social inclusion of young children with DD as they transition into school
- parent resource needs, successes and challenges in promoting their child’s social inclusion
- healthcare and education professionals’ knowledge of DD, resource needs, successes and challenges in promoting social inclusion
Our Approach

• inclusion with appropriate supports

• inter-professional collaboration with parents as fully participating members of the team

• recognition of parents’ critical role in providing connections between their child, the health and education systems, and the broader community
Background

• With increasing numbers of individuals with DD requiring community-based health and social services research has highlighted the need for professionals to have greater knowledge of DD

• Parents have expressed the wish that their expertise be recognized more by professionals

• Parents have expressed concern about the level of knowledge DD healthcare professionals
Objectives for today

Discuss findings re:

• Successful parent professional partnerships
• Knowledge of and training in DD of parents, healthcare professionals and students
• Reported competence of healthcare professionals and students in meeting the needs of children with DD
• Parent professional resource needs
• Discuss implications for improving partnerships
### Sample

#### Parents ($N=230$)

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>22 to 66 years ($M=36.3, SD=7.2$)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>200 (87%) women, 24 (10%) men, 6 (3%) missing</td>
</tr>
<tr>
<td><strong>Relationship to child</strong></td>
<td>212 (92%) biological parents, 6 (3%) adoptive parents, 5 (2%) ‘other’ (e.g., guardian, grandparent), 7 (3%) missing</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td>183 (80%) married/common-law, 40 (17%) single /separated/ /divorced/widowed, 7 (3%) missing</td>
</tr>
</tbody>
</table>
### Sample

#### Children ($N=230$)

<p>| | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>3.0 to 6.9 years ($M = 4.9$; $SD = 6.8$)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>66 (29%) girls 160 (69%) boys 4 (2%) missing</td>
</tr>
<tr>
<td><strong>Primary Diagnosis</strong></td>
<td>105 (46%) Autism spectrum disorder  70 (30%) Unspecified ID/DD  35 (15%) Genetic condition</td>
</tr>
<tr>
<td></td>
<td>* Down Syndrome 24 (10% of total)</td>
</tr>
<tr>
<td></td>
<td>18 (8%) Other (e.g., physical disability; sensory disorder; communication disorder)</td>
</tr>
<tr>
<td></td>
<td>2 (1%) missing</td>
</tr>
</tbody>
</table>
### Sample Medical Students and Physicians

<table>
<thead>
<tr>
<th></th>
<th><strong>Students (N=282)</strong></th>
<th><strong>Physicians (N=12)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>20 to 40 years (M=24.5, SD=2.7)</td>
<td>32 to 64 years (M=46.7, SD=11.4)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>154 (55%) women, 125 (44%) men, 3 (1%) missing</td>
<td>8 (67%) women, 4 (33%) men</td>
</tr>
<tr>
<td><strong>Year in Program</strong></td>
<td>207 (74%) 2(^{nd}) year, 39 (14%) 3(^{rd}) year, 33 (12%) 4(^{th}) year, 1 (&lt;1%) 6(^{th}) year</td>
<td>N/A</td>
</tr>
</tbody>
</table>
# Sample

OT Students and OT Professionals

<table>
<thead>
<tr>
<th></th>
<th>OT Students (N=179)</th>
<th>OT Professionals (N=50)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>22 to 40 years (M=24.8\ SD=2.5)</td>
<td>26 to 57 years (M=40.3\ SD=9.8)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>168 (94%) women 11 (6%) men</td>
<td>47 (94%) women 3 (6%) men</td>
</tr>
<tr>
<td><strong>Year in Program</strong></td>
<td>52 (29%) 1st year 126 (71%) 2nd year</td>
<td>N/A</td>
</tr>
</tbody>
</table>

**Note:** Sample sizes may vary due to data collection methods and response rates.
Measures - Parents

- Open ended survey questions.

“What have been your greatest successes in collaborating with healthcare professionals?”
Parents most successful in collaborating with professionals when...

- they felt well informed about their child’s needs
- they knew what questions to ask
- professionals were responsive to parent concerns
- professionals shared expertise/understood child’s needs
- professionals shared knowledge of appropriate supports
To achieve successful collaboration parents also emphasized the importance of:

- persistence
- taking initiative
- expertise
Measures

Parent Knowledge (survey questions)

- “How much do you understand your child’s development?”

- “How familiar are you with your child’s special needs?”

7 point scale – converted to Low-Medium-High

Beginning to understand >> Understand a great deal
Parents’ self-reported knowledge of child’s “special needs”

- **ASD**
  - $N = 98$
- **Down Syndrome**
  - $N = 22$
Measures- students & professionals

McGill Inclusive Education Questionnaire (Daniel & Cornish, 2006) (adapted version)

• self reported knowledge of DD including assessment/diagnosis & treatment

4 point scale Very limited >>>> Extensive

• self reported level of competence in meeting the needs of children with DD

4 point scale Could meet few needs/not very competent >>>> could meet all needs expertly
Self-Reported Knowledge of DD

- **Med Students**: N = 262
- **OT Students**: N = 137
- **Physicians**: N = 12
- **OT Professionals**: N = 40

![Bar chart showing self-reported knowledge levels for different groups.](chart.png)
Measures: students & professionals

McGill Inclusive Education Questionnaire (Daniel & Cornish, 2006) (adapted version)

- self reported level of competence in meeting the needs of children with DD

4 point scale

Could meet few needs/not very competent >>>>
could meet all needs expertly
Students’ Competency to Meet Needs of Children With DD

- Low Competence
- Moderately Competent
- Very Competent

Percentage of Med Students and OT Students in each competency level.
Measures: All

• Participation in training sessions, conferences or workshops

• Access to information/resources...

• “Do you feel that you have enough access to information or resources to meet the needs of children with DD?”

• If not enough what resources would be most helpful?
DD Training:
Average Number of Sessions

- Med Students: $N = 255$
- OT Students: $N = 174$
- Physicians: $N = 12$
- OT Professionals: $N = 40$
Access to Information:

Do you have enough information about developmental delays or disabilities?
Resources:

Which resources would be most helpful to parents?

- Web-based
- Written
- Workshops/Seminars
- Peers/Colleagues
Resources:

Which resources would be most helpful to students?

- Web-based
- Written
- Workshops/Seminars
- Peers/Colleagues

The diagram shows the percentage of students preferring each resource, with blue bars representing Med Students and red bars representing OT Students.
Resources:
Which resources would be most helpful to professionals?

Resources:
- Physicians
- OT Professionals

<table>
<thead>
<tr>
<th>Resource</th>
<th>Physicians</th>
<th>OT Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web-based</td>
<td>90.0</td>
<td>85.0</td>
</tr>
<tr>
<td>Written</td>
<td>65.0</td>
<td>70.0</td>
</tr>
<tr>
<td>Workshops/Seminars</td>
<td>100.0</td>
<td>95.0</td>
</tr>
<tr>
<td>Peers/Colleagues</td>
<td>60.0</td>
<td>65.0</td>
</tr>
</tbody>
</table>
Conclusions

Parents report strong understanding of their child’s development and special needs

Students and professionals both report relatively limited training in DD

Parents (approx. 50%), students and professionals report that they would like more information about DD.

Need to consider providing information in different formats to meet the needs of different groups
Next Steps

• Larger samples of professionals
• Opportunities for shared learning
• Further research re. the impact of shared learning on parent–professional partnerships
• Educational Resources
Acknowledgments

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