Services for children with Spina Bifida in Ireland: Occupational Therapists perspectives and recommendations

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Background

• National Neurosurgical Centre since 2008
• Incidence of NTD’s 35.4 annually (TSCUH data)
• Prevalence of Neural Tube Defects (NTDs) 1.17 per 1000, 49% = Spina Bifida (McDonnell et al 2014)

• Larger study into health and therapy needs of children with Spina Bifida nationally (n=247 service providers, 155 parents, 4 children)
Aims

• Review of international literature regarding Occupational Therapists (OT)’s and Spina Bifida

• To gather OT’s perspectives and recommendations regarding
  – Frequency of OT
  – Types of OT interventions
  – Presenting difficulties in Spina Bifida relevant to OT

• Develop recommendations to help guide OT’s nationally

Literature Review

Search from Occupational Therapy and various professional backgrounds.

Limits: Date 1980 – 2014, all child, English language, human

Databases

✓ EbscoHost (MEDLINE and CINAHL)
✓ Cochrane
✓ Pubmed
✓ Manually searching reference lists
Literature Review

Role of OT with Spina Bifida/Physical Disabilities

Varied and complex role (Watson 1991) including:
- Developmental assessments
- VMI and Visual Perception
- Upper limb skills
- Feeding and Oral Motor
- Self care (toileting)
- Skin Integrity
- Positioning/Posture Management
- Transfers
- Equipment
- Prevocational exploration


Literature Review Cont.

OT Role with equipment
- Equipment is frequently required and vital for participation and QOL (Johnson et al 2007, Mazur & Kyle 2004).
- OT’s are key professionals involved in seating and wheelchair assessments and prescription (Kenny & Gowran 2014, Wright et al 2010).
- Equipment provision wait time varies nationally (Cullen et al 2012)
Literature Review Cont.

Access and Frequency of OT

• Reduced QOL due to lengthy waiting lists (Feldman et al 2008)
• Need for OT in community MDTs (Carroll et al 2013, Wright et al 2010)
• OT recommended to be part of MDT Spina Bifida clinics (Watson 1991, Delmarva Foundation 2006, Brustrom et al 2012, Ryan et al 1991)
• Complexity requires at least annual reviews at specialist level (Aldana et al 2010, Delmarva Foundation 2006)

Methodology

Phase 1
Quantitative

Questionnaires from Occupational Therapists
n = 77

Quantitative Analysis

Phase 2
Qualitative

Interviews with Occupational Therapist
n = 7

Qualitative Analysis

Phase 3
Combined Analysis

Interpretation of Quantitative and Qualitative Results to develop overall themes
**Questionnaire Questions**

*12. How often are the following functional categories of children with Spina Bifida seen in your service by your profession (CURRENTLY)??

<table>
<thead>
<tr>
<th>Category</th>
<th>Weekly</th>
<th>Every 2 weeks</th>
<th>Monthly</th>
<th>Every 3 months</th>
<th>Every 6 months</th>
<th>Annually</th>
<th>Not seen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infants</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too young to tell mobility level yet</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses wheelchair most of the time</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses splints and walking aids sometimes, wheelchair sometimes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses splints and sometimes needs help</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walks without difficulty (with splints/aid)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Walks without difficulty (without splints/aid)</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, please explain</td>
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<td></td>
</tr>
</tbody>
</table>

**Questionnaire Questions Cont**

- When initial equipment assessments are completed & when recommended

*17. In your professional opinion at what age would you RECOMMEND a child with Spina Bifida should be assessed for their first seating system and wheelchair?

<table>
<thead>
<tr>
<th>Age</th>
<th>0-6 months</th>
<th>6-9 months</th>
<th>9-12 months</th>
<th>12-18 months</th>
<th>18-24 months</th>
<th>24+ months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seating System Assessment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wheelchair Assessment</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

- Wait time for equipment to arrive
- Presenting Difficulties relevant to OT
  - Psychosocial, Speech and Language, and Visual
- Areas of intervention and priorities
RESULTS - OT Sample

N = 77
Years of experience: 8
Number of cases per therapist: 2.8

GENDER
- Male: 16%
- Female: 84%

GEOGRAPHICAL SPREAD
- HSE West: 26%
- HSE South: 26%
- HSE Dublin North East: 20%
- HSE Dublin Mid Leinster: 25%
- HSE Dublin North West: 26%
- HSE South: 3%
- National Service: 3%

GEOGRAPHICAL SPREAD
- HSE South: 26%
- HSE Dublin: 25%
- HSE Dublin North East: 20%
- HSE West: 26%
- HSE Mid Leinster: 25%
- National Service: 3%

Service Setting

Type of Team
- EIT: 36%
- SAT: 29%
- CRC: 9%
- PCCC: 20%
- Other: 6%

Employment Service
- HSE: 36%
- PCCC: 20%
- CRC: 9%
- Joint Initiatives: 12%
- Enable Ireland: 17%
- Voluntary Hospital: 6%
Wait to access OT

How long following referral until 1st appointment

<table>
<thead>
<tr>
<th>Percentage</th>
<th>No waiting list</th>
<th>0-3 months</th>
<th>3-6 months</th>
<th>9-12 months</th>
<th>12+ months</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>32</td>
<td>51</td>
<td>6</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

No waiting list

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Home & School Visits

Home Visits

- Frequently (50+% of your time)
- Occasionally (25+% of your time)
- Rarely (Less than 25% of your time)
- Never

- 7%
- 19%
- 35%
- 39%

School Visits

- 9%
- 9%
- 40%
- 42%

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# Frequency of Review

<table>
<thead>
<tr>
<th>CURRENTLY</th>
<th>INFANTS/PRE MOBILISERS</th>
<th>WHEELCHAIR USERS</th>
<th>MOBILISES WITH SPLINTS</th>
<th>INDEPENDENT MOBILISER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every 2 weeks</td>
<td>Monthly</td>
<td>Every 3 months</td>
<td>Every 6 months</td>
<td>Annually</td>
</tr>
<tr>
<td>Every 2 weeks</td>
<td>Monthly</td>
<td>Every 3 months</td>
<td>Every 6 months</td>
<td>Annually</td>
</tr>
</tbody>
</table>

**RECOMMENDED**

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# Interventions Provided

![Bar chart showing interventions provided](chart)
Equipment Role

Involvement in Equipment Assessment

- Involved in Wheelchair assessments: 87%
- Involved in Stander assessment: 0%
- Involved in Sleep System assessment: 46%
- Involved in splints / orthotics assessments: 25%

Timing of Initial Seating Assessment

- Percentage of respondents
  - 0-6 months: 35%
  - 6-9 months: 25%
  - 9-12 months: 20%
  - 12-18 months: 15%
  - 18-24 months: 10%
  - 24+ months: 5%

- Currently
- Recommended
Other areas to consider

Psychosocial Concerns
- Attention/Concentration (41%)
- Learning/Attainment (36%)
- Reduced self confidence (31%)
- Self esteem issues (27%)
- Reduced quality of life (22%)

Speech and Language Needs
- Language skills (27%)
- Communication (26%)
- Social Skills (21%)
- Feeding (19%)
- Articulation/Phonological difficulties (9%)

Visual Difficulties
- Hand eye coordination (39%)
- Jigsaws or staying within the lines (37%)
- Visual tracking (31%)
- Visual fatigue (30%)
- Noticing details in pictures (26%)

Overall Priorities for OT’s

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipment</td>
<td>100</td>
</tr>
<tr>
<td>Mobility</td>
<td>98</td>
</tr>
<tr>
<td>Pressure Relief</td>
<td>95</td>
</tr>
<tr>
<td>Postural mangement</td>
<td>95</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>88</td>
</tr>
<tr>
<td>Self care</td>
<td>83</td>
</tr>
<tr>
<td>Feeding</td>
<td>68</td>
</tr>
<tr>
<td>Hand Function</td>
<td>63</td>
</tr>
<tr>
<td>Speech and Language Skills</td>
<td>46</td>
</tr>
<tr>
<td>Cognitive Ability</td>
<td>44</td>
</tr>
<tr>
<td>Visual Abilities</td>
<td>42</td>
</tr>
</tbody>
</table>
Conclusions
- Implications for Practice

• Small Numbers
  – Liaise with Specialist Service

• Varied Role
  – Requires broad understanding
  – Access to appropriate resources
  – Clarity of role

• More frequent review recommended
  – Ensure sufficient staffing levels to provide appropriate service
  – Consider non-equipment needs
  – Proactive review planning

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Conclusions
- Implications for Practice

• Early wheelchair and seating assessments recommended
  – Ensure earlier initial assessment for wheelchair (18-24 months)
  – Initial seating assessments between 6-9 months
  – Frequent review of equipment

• Complex profile
  – Requires understanding (Barf et al 2003)
  – Impacts on many aspects of occupational performance

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Limitations

• 77 respondents
• Self selecting sample of OT’s
• Not OT specific questions
• Difficult to ascertain frequency of review as variation in needs

Future Research

• Expert opinion and OT specific research
• Outcomes of varied interventions provided
• Child and parental feedback about service

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  Temple Street, Dublin 1

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References


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ANY QUESTIONS???