Occupational Therapy and children with Neuromuscular disorders

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Scope
Foundations & Collaboration

- Promoting health and well being through occupation.

- The primary goal: to enable people to participate in the activities of everyday life. (WFOT)
• *The purpose of science is not to analyze or describe but to make useful models of the world. A model is useful if it allows us to get use out of it.*

Edward De Bono
Foundations & Collaboration

**Figure 3-1** Person-environment-occupation model. (From Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. [1996]. The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy, 63* [1], 9-23.)

Foundations & Collaboration

How do we reach our goals?

• Assessment and co-operation
• Goal setting and planning
• Family and child centred intervention
• Evaluation and follow up
• Only if we can measure a phenomenon in a reliable way can we make progress toward the goal of defining disorders, implementing treatments, and demonstrating that our interventions work.

Emde et al, 2005 pg 37
Standardised Assessments

- Paediatric Evaluation of Disability Inventory
- School Function Assessment
- Perceived Efficacy of Goal Setting
- Functional Independence Measure for Children
Foundations & Collaboration

Upper Limb Assessments

- Dynamometry & Pinch Test
- Manual muscle testing
- Jebsen Hand Function Test
- Range Of Movement measurements
Foundations & Collaboration

How do we reach our goals?

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Foundations & Collaboration

How can I access OT services for my child?

- Identified need for Occupational Therapy
  - Is need at school?
    - School submits funding application & contact service provider
  - Is need at home?
    - Referral to local Community Health Centre
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Finding an OT:

• Early Childhood Intervention Services
• School
• Local Community Health Centre
• Neuromuscular clinic, RCH
Foundations & Collaboration

- OT - Hospital
- CHILD / FAMILY
- OT - Home
- OT - School
Case study: Primary School

- Sam
- 7 years with DMD
- Grade 2
- School identified difficulty:
  - completing handwriting tasks
Case study: Primary School

Built up pencil

Angled Writing Board
Case study: Secondary School

- Savant
- 16 years with DMD
- Year 11
- Increased difficulty with writing and typing on computer
Case study: Secondary School

High low bed

Mobile hoist
Case study:
Secondary School

Pressure care mattress

Threshold ramps
Case study: Secondary School

- Savant
- 16 years with DMD
- Year 11
- Increased difficulty with writing and typing on computer

View Video
Funding & Equipment

neater.co.uk
Hand function and Splinting
Hand function and Splinting

- Joint alignment
- Contractures
- Function
- Quality of life
Victorian Aids & Equipment Program

1. Complete an application form

2. OT Assessment & letter
   - type of equipment needed
   - why it is needed

3. Get your doctor to sign a form that says you have a disability.
   (This only needs to be done for your first application)

High Low Bed 🔄
The Department of Human Services (DHS)

- Early Choices for preschoolers
- Making a Difference for school-aged children
- Regional Disability Support Initiative is another DHS program and is for all people up to 65 years.
- Contact your local DHS office to find out about these programs.

Threshold Ramp ⇒
ECIS Flexible Support Packages

- Early Childhood Intervention Services
- Time-limited support
- Department of Education and Early Childhood Development
Links with local disability networks
- Scope
- www.ourcommunity.com.au
- Contact your local council

Local service clubs
- Rotary
- Apex
- Local RSL
- Lions Club
• Local radio or newspapers
• Major companies
• Do your own fundraising
Vehicle Modification Subsidy

- June 2008 Vehicle Modifications are part of the Victorian A&EP.
- The person has to be eligible under A&EP Eligibility guidelines.
- Capacity exists to provide assistance to:
  “People with a disability requiring modifications to travel as passenger in their primary vehicle, including children and their family”
A&EP Vehicle Modification Subsidy

What dollars are provided?

- Subsidy Maximum $10,000
- Partial subsidy can be applied for and further applications can be submitted up to the maximum over a seven (7) year period.
- No funding is retrospective.

Phone: 1800 995 009
Email: vmss@bhs.org.au
A&EP Vehicle Modification Subsidy

What is funded?

• All modifications need to comply with:
  ▪ Australian Design Rules
  ▪ VicRoads Standards for Registration.
• Modifications only - not car purchase
• Web: www.dhs.vic.gov.au/ds/aep
Funding & Equipment

Victorian Aids & Equipment Program

- Complete an application form

- OT Assessment & Letter
  - type of equipment needed
  - why it is needed

- Doctor to confirm disability.
  (This only needs to be done for your first application)
Where else can I go for help?

• Scope Equipment Resource
  ▪ www.scopevic.org.au
  ▪ Statewide Specialist Services 8311 4000

• Disability Online
  ▪ www.disability.vic.gov.au

• Association for Children with a Disability
  ▪ 03 9818 2000 or 1800 654 013 (non metro)
  ▪ www.acd.org.au
  ▪ Through the Maze: A Guide
Transitions
Transitions

Link with services early!

• Home
  – Consider - wheelchair access - Ramps
  – Bathroom – rails, graded shower floor, commode
  – Doorways – width, turning circles
  – Bedrooms – bed transfers, hoists

• Transportation
  – Car transfers
  – Vehicle modifications
At school

- OT Environmental Assessment upon enrolment
- a fully accessible school environment
- a supportive & accessible curriculum
  - consider technology
- appropriate educational and care support
Transitions

At school

- staff training
- collaborative working with parents and other professionals
- positive messages about disability for the child, other students & adults within the school
How to access other helpful services:

- **TADVIC**
  - www.tadvic.asn.au

- **Independent Living Centre**
  - www.ilcaustralia.org.au

- **Archicentre**
  - www.archicentre.com.au
THANK YOU!

- Families and patients
- Muscular Dystrophy Association
- Paula Bray, Westmead Children’s Hospital, Sydney
- Community OT’s
- Scope Victoria
- RCH OT Department
### Contact Details

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References


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