Parenting with intellectual disability

The Australian Perspective

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Overview of presentation

1. History and development of Healthy Start

2. The Healthy Start model

3. Evaluation of first 3 years

4. The next 3 years
History of Healthy Start

• Prior to Healthy Start in Australia
  – No organized approach to supporting with parents with intellectual disability
  – Two independent research teams (PRC & Uni Sydney)
PRC research pre 2005

• PYC

• Family-centered practice

• Practitioner support

• Video-modelling
Uni Sydney research

• Healthy & Safe

• Social Support


Uni Sydney research

• Health/experience of mothers


• Antenatal outcomes

• Development of children
Uni Sydney research

• Child protection & court system


History of Healthy Start

• Prior to Healthy Start in Australia
  – No organized approach to supporting with parents with intellectual disability
  – Two independent research teams (PRC & Uni Sydney)
  – National Forum in 2004
Healthy Start aims to support practitioners, managers, researchers and policy makers to access and exchange knowledge, resources and expertise to better meet the needs of these families.
Knowledge & resource development for capacity building & dissemination

Healthy Start National Team (Parenting Research Centre & University of Sydney)

Drive innovation & new knowledge

Develop evidence informed best practice approaches

Drive knowledge translation for the field

Drive two way exchange of knowledge with the field

Provide National Coordination of Healthy Start activities

Dissemination activities that facilitate capacity building

Education and training

- Online unit of study “Parenting with a developmental disability”
- Training in evidence based parent education programs

Access to resources

- Healthy Start website
- Healthy Start E-network
- Healthy Start Listserv

Research and Development

- Develop innovative resources
- Address gaps in knowledge and practice

Networks that enable Capacity building & dissemination

Healthy Start Learning Hubs across Australia

Hubs are hosted by an agency

Led by a Hub Convenor

Contain cross-sectoral and multi-agency membership

Develop Local Action Plans to address needs in local communities

Disseminate training and resources to local members

Provide feedback to the Healthy Start National team.
Local level
Over 60 Learning Hubs created to support local networks of practitioners
Over 100 Learning Hub Convenors planning and coordinating activities and agencies
Over 130 families in parenting programs

National level
National network resourcing practitioners with a website, news alerts, newsletter, listserv
Over 300 practitioners accessing telephone support
Over 530 practitioners trained in evidence-based programs: Parenting Young Children and Healthy and Safe. An Australian Parent Education Kit
Over 50 families in a pilot of innovative resources: Healthy Start for Me and My Baby and Australian Supported Learning Program: Me and My Community
Online study offered through the University of Sydney: Parenting with a Developmental Disability

State level
National Team providing leadership and support for learning hub convenors in every state and territory

Over 60 learning hubs across Australia

4
1
14
1
7
14
2
18
Healthy Start project logic
Outcomes

Proximal outcomes → Intermediate outcomes → Distal outcomes

- Capacity
- Practice change
- Family capacity/resources
  Parent/child relationships
- Child health & development
Healthy Start Approach

• Build knowledge & expertise through exchange & collaboration
• Opportunities for education & training
• Research in identified gap areas
• Building leadership networks
History and development of Healthy Start

- Phase 1: 2005-2008
  - Building local leadership & national practice networks
  - Evidence-based parenting education programs
  - Innovative parenting education resources
What we achieved

• 67 active Learning Hubs (pre-post data for 36)
• Parent education training for 394 practitioners (122 families)
• 2000+ members
• Valued website resource
• ASLP: Me and My Community
Parent Education
Background

Figure 1. Historical timeline of published studies of parent training interventions for parents with ID.

*Includes 2 replication studies published prior to 1994 but not included in Feldman’s (1994) review.
Home dangers, health & emergencies
Results of efficacy trial

- H&S associated with increases in:
  - recognition and management of home dangers
  - identification and implementation of precautions in the home
  - parents’ understanding of health & illness*
  - Parents’ knowledge of skills to manage emergencies*
  - Parents knowledge about visiting doctor*
  - Parents’ knowledge and skills about using medicine’s safely*

- Other conditions also led to increases in learning
- Many gains maintained at 3 month follow-up
Strengthening skills in child care and building positive and stimulating parent-child interactions
Efficacy Trial - Method
(Mildon, et al., 2008)

- **Participants**
  - N = 24 (Age range mothers 20-49; fathers 30-49)
  - Children aged 16 to 70 months

- **Design**
  - Single group repeated measures
  - Weekly visits of approx 90 minutes for 6 months (10-26 sessions)
Results of Efficacy Trial

- Reduced parent stress
- Reduced child disruptive behaviour
- Older children: home environment quality improved
- Increased parent satisfaction and confidence
- Many changes maintained at follow-up
- Goodness-of-fit rated positively
Research Question

How effective are *Healthy and Safe* and *Parenting Young Children* when delivered as part of a multi-site clinical trial delivered by a diverse range of professionals?
Method

• Design
  - Multi-site trial
  - 3 phases of training

• Participants
  - 394 practitioners trained in 2006-2007
  - 87 began program with 1+ family
  - 36 completed program with 1+ family
  - 122 parents began program
Method

- 122 families
  - 93% mothers
  - 33% attended special school
  - Children aged birth to 7 years ($M = 2$ years, $sd = 20$ months); 55% boys; 92% living at home
  - Post data from 49 families
  - Follow-up data from 23 families
# Pre-, post-intervention and follow-up mean and rank sum values on parenting practices scales for Parenting Young Children participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Possible range</th>
<th>Pre-intervention</th>
<th>Post-intervention</th>
<th>Follow-up</th>
<th>z(^b)</th>
<th>p</th>
<th>d(^c)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parenting Warmth</td>
<td>1.83-9.14</td>
<td>n=28 7.25 (1.67)</td>
<td>n=25 7.52 (1.36)</td>
<td>n=15 7.68 (1.75)</td>
<td>-1.064</td>
<td>.287</td>
<td>.27</td>
</tr>
<tr>
<td>Parent Involvement</td>
<td>1-5</td>
<td>n=28 1.13 (0.76)</td>
<td>n=24 1.24 (0.47)</td>
<td>n=13 1.43 (0.79)</td>
<td>-2.000</td>
<td>.045</td>
<td>.19</td>
</tr>
<tr>
<td>Parent Efficacy at Child</td>
<td>1-5</td>
<td>n=28 2.89 (1.07)</td>
<td>n=25 3.16 (.90)</td>
<td>n=14 3.64 (.74)</td>
<td>-1.169</td>
<td>.243</td>
<td>.41</td>
</tr>
</tbody>
</table>

\(^a\) Missing data may have meant that scale scores could not be calculated for all 28 participants at post-intervention or for all 18 participants at follow-up.

\(^b\) Based on Wilcoxon Matched-Pairs Signed Ranks Test of difference between the ranked sums of matched pre-intervention and post-intervention values.

\(^c\) Cohen’s d calculated using pre-intervention standard deviations.
### A national strategy for children of parents with learning difficulties

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<th>p</th>
<th>d^c</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Comprehension</td>
<td>0-3</td>
<td>19</td>
<td>2.42 (.77)</td>
<td>16</td>
<td>2.56 (.73)</td>
<td>5</td>
<td>2.60 (.55)</td>
</tr>
<tr>
<td>Illness and Symptom Recognition</td>
<td>0-25</td>
<td>16</td>
<td>10.25 (4.07)</td>
<td>14</td>
<td>16.21 (9.46)</td>
<td>4</td>
<td>19.0 (9.76)</td>
</tr>
<tr>
<td>Life-Threatening Emergencies</td>
<td>0-12</td>
<td>18</td>
<td>3.44 (2.71)</td>
<td>16</td>
<td>6.94 (2.86)</td>
<td>5</td>
<td>6.40 (2.70)</td>
</tr>
<tr>
<td>Going to the Doctor</td>
<td>0-9</td>
<td>18</td>
<td>3.67 (1.88)</td>
<td>16</td>
<td>5.63 (1.67)</td>
<td>5</td>
<td>5.20 (2.17)</td>
</tr>
<tr>
<td>Using Medicine Safely</td>
<td>0-6</td>
<td>18</td>
<td>1.67 (1.53)</td>
<td>16</td>
<td>3.25 (1.34)</td>
<td>5</td>
<td>2.80 (2.17)</td>
</tr>
</tbody>
</table>

^a Missing data may have meant that scale scores could not be calculated for all 21 participants at post-intervention or for all 5 participants at follow-up.

^b Based on Wilcoxon Matched-Pairs Signed Ranks Test of difference between the ranked sums of matched pre-intervention and post-intervention values.

^c Cohen’s d calculated using pre-intervention standard deviations.
Conclusions

PYC
• Sig. improvements in parent involvement
• Sig. improvements in the variety of activities available to the child at home
• Mod. change in parent efficacy at child care tasks
• Mod. change in a number of aspects of the home environment

H&S
• Sig. improvements in many aspects of parent knowledge of health and safety
• Mod. change in home & precautions
Family characteristics may influence intervention outcomes

Family contextual factors may influence program outcomes.

What role do factors such as socio-economic disadvantage, social support, and parent mental health play in intervention effectiveness for parents with intellectual disability?
Aspects of service delivery may influence intervention outcomes

<table>
<thead>
<tr>
<th>Reason for drop out</th>
<th>% drop out</th>
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<tbody>
<tr>
<td>Practitioner changed job</td>
<td>20%</td>
</tr>
<tr>
<td>Child no longer with the family</td>
<td>14%</td>
</tr>
<tr>
<td>Family moved out of service area</td>
<td>12%</td>
</tr>
<tr>
<td>Other family related circumstances</td>
<td>9%</td>
</tr>
<tr>
<td>Practitioner drop out</td>
<td>4.6%</td>
</tr>
<tr>
<td>Time limited service</td>
<td>3%</td>
</tr>
<tr>
<td>Family requested the program stop</td>
<td>3%</td>
</tr>
<tr>
<td>Little or no change happening</td>
<td>3%</td>
</tr>
<tr>
<td>Another service became involved</td>
<td>3%</td>
</tr>
<tr>
<td>Family not responding/not home</td>
<td>1.5%</td>
</tr>
</tbody>
</table>
Common Barriers

Barriers to training transfer (Burke & Hutchins, 2007)

- Those related to the individual
- Those related to the work environment
- Those related to the innovation itself
How many families have actually received a program?

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Number of practitioners eligible to deliver a program</td>
<td>394</td>
</tr>
<tr>
<td>Number of families who commenced a program</td>
<td>122 (31%)</td>
</tr>
<tr>
<td>Number of families who completed a program</td>
<td>49 (12%)</td>
</tr>
</tbody>
</table>

31% service transfer – families got something

12% service transfer – families completed a program
Parenting Young Children
Ett utbildningsprogram i hemmiljö
Producerat av The Parenting Research Centre
History and development of Healthy Start

- Phase 2: 2008-2009
  - Consolidation of Phase 1
  - Hub convenors
  - Grants for LAAP
  - Website
  - Training
  - New research
History and development of Healthy Start

• Phase 3: 2009-2011
  – Focus on individuals as experts
  – Strengthen collaboration within the national practice network
    • Website redevelopment
    • National Forum in May 2010
    • 8 collaborative projects
  – Continuing new research and development
History and development of Healthy Start

- Phase 4: 2011-2014
  - Research translation
  - Consolidating a national practice network
  - Leadership development
  - Prevalence study
  - Wider cross-sectoral promotion of Healthy Start
Critical success factors

- Leadership at national level
- Local leadership
- Resources (website, tools, programs, education)
- Organisational backing (host agency)
- Local action
Lessons from Healthy Start

• Experts are key
• Build on pockets of good practice
• The 3 C’s
• Buy-in from the “Practice Network” through collaboration is essential
• Tools for collaboration
• two-way communication
• Local needs & local solutions
A real opportunity...

THE UNIVERSAL DECLARATION
OF Human Rights
How to get involved in Healthy Start

You can be part of the practice network at the level that suits you:

• Connect (website)
• Communicate (e-news, forums)
• Collaborate (forums, email)
• Innovate (forums)
Find out more

www.healthystart.net.au

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