Group Mindfulness-Based Intervention for parents of children/adults with developmental disabilities

Richard Hastings
University of Warwick

Research/practice rationale

• Mindfulness-based interventions have a developing evidence base for reduction of psychological distress
• Parents of children and adults with IDD face multiple stressors relating to transition, availability of services, demands of long term care, and future care concerns
• Positive associations of mindfulness and acceptance with reduced parental distress [e.g., Jones et al., 2014; Lloyd & Hastings, 2008; MacDonald et al., 2010; Weiss et al., 2012]
Mindfulness for parents

• Total of 13+ evaluation studies of mindfulness-based support for parents of children with DD to date, including several RCTs with encouraging results [e.g., Dykens et al., 2014; Ferroli & Harris, 2013; Neece, 2014]

North Wales DD study

• 21 parents of children with autism (16), DS (1), CP (2), general ID (2); ages 4-16 years
• Attended Eluned Gold’s Mindfulness-Based Well-Being Course for Parents (MBW-P)
• Primary aim: increase participants’ mindful awareness, whilst recognizing the shared experiences and difficulties encountered by parents
• Weekly 2hr sessions: Mindfulness practice exercises, reflect on practices (inquiry) as a group/in pairs, orientation to home practices, reflection on home practices from previous week
• CD of short practices 5--20 minutes each
### MBW-P content

<table>
<thead>
<tr>
<th>Session content</th>
<th>Home practice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Automatic Pilot</strong></td>
<td>Introductions, ground rules; raisin meditation; breath in body practice</td>
</tr>
<tr>
<td><strong>2 Room to Breathe</strong></td>
<td>Breath in body practice; reflection on home practice; body scan; linking awareness of body, thoughts, emotions; planting seeds of kindness</td>
</tr>
<tr>
<td><strong>3 Learning about Stress</strong></td>
<td>Breath in body practice; reflection on home practice; mindful movement practice; three step breathing space</td>
</tr>
<tr>
<td><strong>4 Working with Stress</strong></td>
<td>Mindful movement practice; reflection on home practice; three step breathing space; learning about affect systems; awareness of breath practice</td>
</tr>
<tr>
<td><strong>5 Responding to Difficulties</strong></td>
<td>Awareness of breath practice; exploring difficulty; learning to respond rather than react; mindful movement practice; three step breathing space</td>
</tr>
<tr>
<td><strong>6 Communication</strong></td>
<td>Sitting practice; reflection on home practice; movement practice; mindful listening practice; discussing patterns of communication</td>
</tr>
<tr>
<td><strong>7 Living our Lives</strong></td>
<td>Sitting practice; reflection on home practice; movement practice; discussing values;</td>
</tr>
<tr>
<td><strong>8 Rest of our Lives</strong></td>
<td>Sitting practice; reflecting on home practice; discussing how to continue with practices; movement practice</td>
</tr>
</tbody>
</table>

### Pre-post outcomes

<table>
<thead>
<tr>
<th>Parent Measure</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Five Facet Mindfulness Questionnaire Total Score</td>
<td>0.49</td>
</tr>
<tr>
<td>Self-compassion</td>
<td>0.39</td>
</tr>
<tr>
<td>Stress (from DASS)</td>
<td>0.49</td>
</tr>
</tbody>
</table>
Mindfulness for parents

• Some older parents included in DD studies to date, but mainly parents of children and young people - intervention not targeted for older parents
• Lunsky et al. (2015) – development and pilot pre-post test of mindfulness for parents of adults (adapted MBCT)
• Lack of active control conditions (except Dykens et al. – Positive Adult Development)

Mindfulness-Based Intervention for parents of adults with ID: Outcomes from a randomised active treatment controlled trial

Yona Lunsky, Richard Hastings, Sue Hutton, Carly McMorris, Anna Palucka, Jonathan Weiss, Karen White
Study aims

- Work in partnership with community support agencies to provide programmes for parents of adults with IDD (“DSO’s”)
- Pilot RCT test of Lunsky et al.’s mindfulness group intervention
- Incorporate active comparison – an alternative group intervention
- Examine some feasibility questions – recruitment, retention/attendance in the groups, retention to data collection follow-up

Both interventions

- Offered to parents on the waiting list for DSO services
- Were 6 weeks long, 2 hours weekly
- Involved parents accessing DSO services
- Allowed for some informal parent support
- Were held at the Toronto DSO with optional childcare
- Offered parents something to help them cope with their current situation
- Run 4 times during the study
Support and Information

• Getting to know Adult Developmental Disability Services
• Person Directed Planning
• Taking care of us: Caregiver issues and Respite services
• Specialized clinical services
• Connectability overview (website with resources); fee for service, advocacy and parent support groups
• Residential alternatives
• Crisis supports
• Family support workers and role of Adult Protective Service Workers Roles

Mindfulness

Session 1  Getting off Automatic Pilot
Session 2  Observing and Non-Judgmental Acceptance
Session 3  Thoughts are not Facts
Session 4  Taking Care of Myself
Session 5  Turning Towards Difficulties
Session 6  Continuing with Mindfulness
Participants

• Parents - 57 parents participated in groups in total; age range 37-81 years; diverse in terms of culture and SES

• Their children - age range 16-40 years; in addition to their developmental disability had several other health problems; 44% had autism

• 8 adult children used on-site respite during group time

Procedure

<table>
<thead>
<tr>
<th>Recruit</th>
<th>Baseline measures</th>
<th>Randomise</th>
<th>Intervention</th>
<th>8 weeks post-group</th>
<th>20 weeks post-group</th>
</tr>
</thead>
</table>

• 138 parents expressed an interest, 81 excluded
• Data from 4 parents in mindfulness and 2 in S&I excluded as in a couple, 1 parent problems with English = 50 for analysis (26 mindfulness, 24 S&I)
• Mindfulness – 100% data, 100%, 77%
• S&I – 100%, 83%, 71%
Outcome measures

• **Primary outcome** – 14 stress and depression items from the DASS-21

• **Secondary outcomes:**
  – Bangor Mindful Parenting Scale, Five Facets Mindfulness Questionnaire
  – Family Empowerment Scale
  – Caregiving Burden 9-item subscale of the Revised Caregiving Appraisal Scales
  – Self-Compassion Scale Short Form
  – Positive Gain Scale

---

Primary outcome results

![Primary outcome results graph](image)

ANCOVA T1, controlling baseline p=.001 ($d= .81$); effect maintains to T2
Secondary outcome results

<table>
<thead>
<tr>
<th>Measure</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Family Empowerment Scale: services</em></td>
<td>0.349</td>
</tr>
<tr>
<td>Family Empowerment Scale: family</td>
<td>0.093</td>
</tr>
<tr>
<td><em>Five Facet Mindfulness Questionnaire Total Score</em></td>
<td>0.258</td>
</tr>
<tr>
<td>Bangor Mindful Parenting Scale</td>
<td>0.086</td>
</tr>
<tr>
<td>Burden</td>
<td>0.24</td>
</tr>
<tr>
<td>Self-compassion scale</td>
<td>0.118</td>
</tr>
<tr>
<td>Positive Gain Scale</td>
<td>0.054</td>
</tr>
</tbody>
</table>

Other findings

- Mean attendance 4.89 mindfulness sessions; 4.29 S&I sessions (including orientation)
- Satisfaction – asked about 10 aspects of satisfaction with the groups
  - Mindfulness 82.3% satisfied with all 10 aspects
  - 80% for S&I
- Barriers: Childcare (cost, stress of bringing child), Transportation (distance, mode of transit), Language barriers, Location/time of groups (downtown vs. suburbs, daytime vs. evenings)
Comments - Mindfulness

“....Being with others that are living the same life experience that I am, dealing with a disabled young adult”

“I found the mindfulness so very helpful as I navigated some of the difficult emotions that were coming up, as well as the fear I was experiencing....”

Comments – S & I

“A chance to meet with professionals and able to share my own insights as to what may be more effective in planning for future services”
“It simply makes sense to learn from other families.”
“Made me aware of the significant challenges that were being faced by others and less alone”
“It was like visiting a world where people had the same life problems as me”
“We don’t know what we don’t know. These sessions were a starting point for getting more information about the sector”
Next steps – Toronto study

• Lack of mindfulness practice outside of group
• Facilitation requires specific expertise
  – Familiarity with developmental disability sector
  – Training in mindfulness-based approaches
• Considering train-the-trainer approach (cf. Dykens training parents approach)
  – Develop more leaders with expertise to deliver groups more broadly by pairing facilitators
• Exploring feasibility of more virtual groups so that expertise could be available more widely

Funding:
• Health and Care Research Wales Social Care PhD Studentship
• Developmental Services Research Grant Fund, Ministry of Community and Social Services, Ontario, Canada

R.Hastings@warwick.ac.uk
@ProfRHastings