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# Listening to Mothers: Experiences of Mental Health Support and Insights into Adapting Psychological Therapy for People with Severe or Profound Intellectual Disabilities

## And Clinical Research Portfolio

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# CHAPTER ONE: SYSTEMATIC REVIEW

*Increasing Indices of Happiness in Individuals with Severe or Profound Intellectual Disabilities: A Systematic Review of the Literature.*

**Tracey M Adams\***

Prepared in accordance with authors instructions for the Journal of Applied Research in Intellectual Disabilities (JARID) (see Appendix 1.1)

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## Abstract

**Background:** Research studies have used behavioural indicators of happiness to examine the effects of interventions designed to improve mood in individuals with severe or profound intellectual disabilities. This systematic review provides an overview of the literature aimed at increasing indices of happiness in individuals with severe or profound intellectual disabilities.

**Method:** A computerised search of electronic databases was completed. Twelve studies met inclusion criteria for this review. A quality rating protocol was devised and included studies were rated on their methodological quality.

**Results:** Included studies used three different intervention methods: structured stimulation, favourite stimulation delivered during exercise engagement, and microswitch interventions. There was evidence for the effectiveness of microswitch and exercise engagement interventions in increasing participants indices of happiness.

**Discussion:** A major flaw of research in this area is small sample sizes. Future reviews could aim to conduct a meta-analysis of existing study findings, to appraise the effectiveness of interventions.

**Key words:** happiness indices, mood, intellectual disability, intervention

## Introduction

Although there are varying definitions in the literature, it is generally agreed that individuals with severe or profound intellectual disability are at an early stage of intellectual, communicative, social and emotional development, and usually require intensive support with activities of daily living, including self-care and mobility. In addition, individuals frequently have physical or sensory difficulties including hearing or vision impairment, and experience significant health issues, such as epilepsy (Bellamy et al., 2010).

Individuals with severe or profound intellectual disabilities have limited receptive and expressive language abilities, and mainly rely on pre-verbal communication, such as gestures, vocalisations, and body and facial expression (Carr et al., 2016). While those with more severe impairments have the capacity to experience an emotional life, assessing their affective state is difficult, given individuals cannot report how they are feeling. Researchers have responded to this challenge in a number of ways, including asking key informants to provide proxy reports of individuals' mood (Ross & Oliver, 2003). However, there have been concerns about the accuracy of proxy reports in relation to subjective experience (Emerson, Felce & Stancliffe, 2013). Identifying objective behavioural indicators of affect may offer a more valid way of estimating an individual's mood (Ross & Oliver, 2003).

Green & Reid (1996) used behavioural indicators to measure happiness in individuals with severe or profound intellectual disabilities. This study operationally defined behaviours that are generally agreed to be indicative of an individual's happiness, such as smiling and laughing, and labelled them 'indices of happiness'. Indices of happiness were reliably observed when individuals were presented with their most preferred stimuli such as toys, verbal interaction and their favourite drink, as compared to their least preferred stimuli. Evidence for the validity of using indices of happiness was demonstrated by a strong association between behaviourally defined happiness indices, and ratings of participant

happiness levels by familiar professionals, when watching video footage of the participants when they were presented with preferred stimuli (Green & Reid, 1996).

Further research has used indices of happiness to examine the effects of interventions designed to increase happiness. This research has typically used single-case research designs and involved small numbers of participants. Lancioni et al. (2005a) and Dillon & Carr (2007) conducted reviews of the literature concerning interventions designed to increase indices of happiness in people with severe or profound intellectual disabilities. The three main intervention methods presented by Lancioni et al. (2005a) and Dillon & Carr (2007) will be the focus of this review. These methods are: structured stimulation interventions; favourite stimulation automatically delivered on exercise engagement, and microswitch interventions.

Green & Reid (1996) implemented a structured stimulation intervention called the 'fun time' programme. This involved the researchers presenting individuals with profound intellectual disabilities with their favourite stimuli such as toys and social interaction for 1-3 minutes, every 10 minute intervention session. Favourite items and activities were identified using stimulus preference assessment (Green et al., 1988). This involves repeatedly presenting a variety of stimuli to an individual and determining which stimuli the participants consistently approach, to differentiate preferred from non-preferred stimuli. This study found increased participant indices of happiness with presentation of preferred toys and social interaction. Ivancic et al. (1997) replicated the 'fun time' structured stimulation intervention with individuals with profound intellectual disabilities, some of whom had minimal movement abilities. Preferred stimuli such as doll play and massage were chosen by staff familiar with the participants. Increased indices of happiness were found with intervention for the individuals in the 'movement group'. However, participants in the 'minimal movement' group showed no behavioural indicators of happiness.

Other research has aimed to assess if pairing exercise with an individual's favourite stimuli improves exercise engagement and behavioural indicators of mood. In Lancioni et al.'s (2004a) study, two participants received their identified favourite stimuli, such as music and vibratory input, for engaging in exercise on a stationary bicycle and a stepper device. Increased exercise responses and indices of happiness were found during the intervention, with delivery of preferred items for both participants. These findings have been replicated using different participant exercises, such as foot and leg movements (Lancioni et al., 2005b).

Whilst previous studies have shown that exposure to preferred items and activities improves participants' happiness indices, other research has advocated that individuals should have a more active role in accessing their preferred stimuli. The self-determination literature highlights the importance of individuals having agency over their own lives (Wehmeyer & Abery, 2013). Microswitch-based interventions may aid self-determination by allowing participants to: (i) choose when they would like to access their preferred items or activities; (ii) decide between two or more favourite stimuli, and (iii) initiate social interaction (Roche et al., 2015). Lancioni et al. (2002) compared the effectiveness of a microswitch-based intervention with a structured stimulation intervention in improving indices of happiness. The microswitch intervention involved participants performing a certain response such as head turning, which activated a microswitch to produce brief periods of preferred stimulation, such as familiar voices, songs and flickering lights. This study found comparable results for both interventions in increasing indices of happiness, such as smiling and laughing. However, given that microswitch interventions promote self-determination, this may be a preferable intervention for individuals.

Since Lancioni et al. (2005a) and Dillon & Carr's (2007) reviews, further intervention studies have been published which aim to improve the mood of people with severe or profound intellectual disabilities. In addition, both Lancioni et al. (2005a) and Dillon &

Carr's (2007) reviews did not undertake a quality appraisal of the studies they included. The

present paper aims to provide an updated systematic review and quality appraisal of the

research literature regarding interventions designed to increase indices of happiness in

individuals with severe or profound intellectual disabilities.

# Methods

## *Search Strategy*

The following databases were used: MEDLINE (via Ovid Medline (R) in-process and other non-indexed citations, and Ovid Medline (R) 1946 to present, last accessed on 3rd March 2018); Embase (via Ovid Embase, 1947 to present, last accessed 3rd March 2018); CINAHL (via EBSCO host 1983 to present, last accessed on 3rd March 2018); PsychINFO (via EBSCO host 1894 to present, last accessed on 3rd March 2018); Cochrane Library (inception date of database to last accessed 3rd March 2018); Scopus (inception date of database to last accessed 3rd March 2018). An additional hand search of the reference sections of the final included studies and of relevant review articles in the area was completed (Dillon et al., 2007; Lancioni et al. 2005a).

The search terms were matched onto database subject headings and the results were combined. The search terms included 'severe or profound intellectual disability' and 'indices of happiness', as detailed in Table 1. An additional key word search was also combined to ensure a sensitive search of the literature. The key word search was applied to the title and abstract search fields of databases. A detailed description of the search strategy for each database is included in Appendix 1.2.

**Table 1.** Database search terms

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(profound *OR* severe) n3 (learning disabilit* *OR* intellectual disabilit* *OR* learning difficult* *OR*
developmental disabilit* *OR* developmental disorder* *OR* multiple disabilit* *OR* disabilit*)
*OR*
(profound intellectual n2 multiple disabilit*)
*OR*
(profound n2 multiple learning disabilit*)
*OR*
(profound *OR* severe) n3 (mental retard* *OR* retard* *OR* cognitive dysfunct* *OR* disabled)
*OR*
(PMLD *OR* PIMD *OR* PMD)

*AND*

(happ* *OR* happ* indic*)

---

### *Study Selection*

Inclusion criteria for this review were: (i) published in a peer review journal; (ii)

inclusion of individuals with severe or profound intellectual disability; (iii) presentation of

individual or group data on indices of happiness; (iv) intervention study published in year

2006 onwards (after previous review articles on this topic), and (v) participants aged 16 years

and over. Studies using younger participants were included if data was presented separately

for participants 16 years and older. Review articles and dissertations were excluded.

Databases were searched using the terms outlined above, and duplicate articles were

removed. The remaining article titles were read for relevance to the review topic (n=1,652),

with 1,524 studies excluded. Abstracts of potentially relevant articles were then read (n=128),

and the study inclusion/ exclusion criteria was applied. Sixty six articles were excluded, and a

review of full text articles (n=62) were carried out. A total of thirteen studies were initially

selected for inclusion in this review. Figure 1 shows the process of identifying studies for

inclusion.

```
┌─────────────────────────────────────────┐
│ Initial Electronic Search and Hand Search│
│ Ovid - Medline, Embase            996    │
│                                          │
│ EBSCOhost – CINAHL, PsycINFO      761    │
│                                          │
│ Scopus                            535    │
│                                          │
│ Cochrane Library                   2     │
│                                          │
│ Hand Search                        6     │
│                                          │
│ (n= 2,300)                               │
└─────────────────────────────────────────┘
```

Duplicates removed= 648

Screening of titles (n=1,652)

Excluded (n=1,524)
Unrelated to review topic

Review of abstracts (n=128)

Excluded (n=66)
Review paper
Mild/ Moderate LD population
Physical disabilities population
Unrelated to review topic

Review of full articles (n= 62)

Excluded (n=49)
Dissertations
Published before year 2006
Participant ≤ 16 years of age
No indices of happiness data
Unrelated to review topic

Quality criteria applied (n=13)

Excluded (n=1)
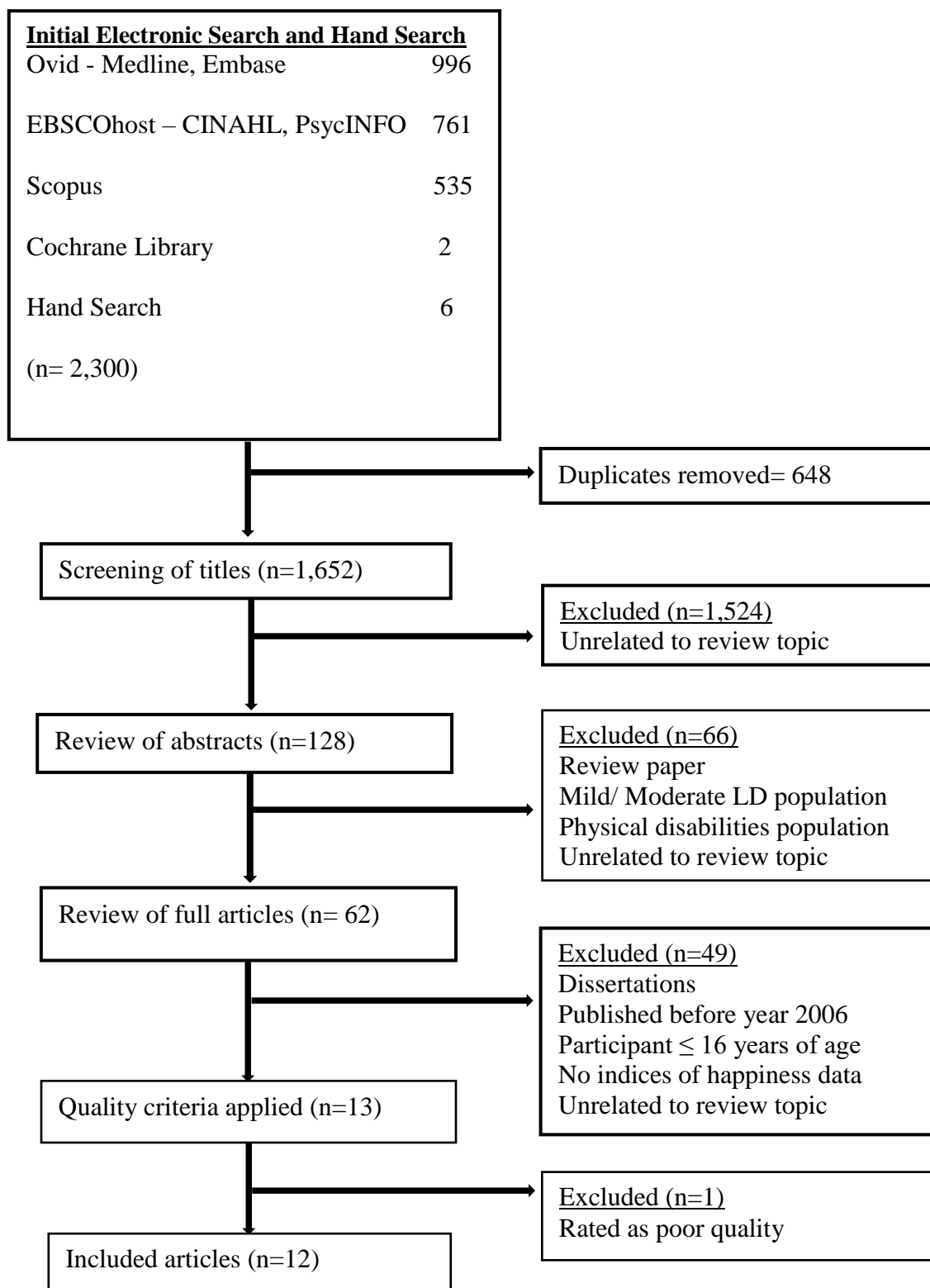Rated as poor quality

Included articles (n=12)

**Figure 1.** Flow chart illustrating the process of identifying studies for inclusion.

*Quality Appraisal*

The Single-Case Reporting Guideline In Behavioural Interventions (SCRIBE; Tate et al., 2016), The 15-item Risk of Bias in N-of-1 Trials RoBiNT Scale (Tate et al., 2013), and guidelines published by the Scottish Intercollegiate Guidelines Network (SIGN, 2007), were used to develop the quality rating protocol for the single-case research included in this review (Appendix 1.3). A description of the criteria included in the quality rating protocol is listed in Table 2. Each study was awarded points for each item, with a maximum score of 19. To categorise the overall quality of the papers, it was determined that: good quality= majority of criteria met (score of 15-19); moderate quality= most of the criteria met (score of 10-14); poor quality= most of criteria not met (score ≤ 9). Each item on the protocol was weighted equally, similar to the RoBiNT scale as mentioned above (Tate et al., 2013).

To ensure consistency in quality rating, a second independent rater also assessed half of all included papers. Agreement was found on all six co-rated papers (both gave the same overall rating of good, moderate or poor quality). Discussion took place between raters to ascertain agreement if quality ratings on individual items differed.

**Table 2.** Quality rating protocol assessment criteria

| | | |
|---|---|---|
| 1. Design | • | Is an experimental single-case study design used? |
| | • | Is randomisation used? |
| 2. Blinding | • | Is blinding used? |
| 3. Participants | • | Method of recruitment described? |
| | • | Demographic information described? |
| | • | Standardised assessment of level of intellectual disability? |
| 4. Measures | • | Operational definitions of target behaviour clearly defined? |
| | • | Interobserver agreement evaluated? |
| 5. Intervention | • | Therapeutic setting and location described? |
| | • | Baseline and intervention conditions clearly described? |
| | • | Procedural fidelity evaluated? |
| 6. Analysis | • | Data analysis appropriate to design? |
| | • | Dropouts reported with reasons given? |
| | • | Raw data presented for each measurement point? |

*Data extraction*

A data extraction tool (Appendix 1.4) was used to systematically record important study information. Information relating to study and participant characteristics, measures and results were extracted from the included studies.

# Results

*Quality ratings of studies*

One study was rated as good quality, eleven studies were rated as moderate quality, and one study as poor quality. Further information about the breakdown of quality ratings of studies is available in Appendix 1.5. It was deemed appropriate that the paper of poor quality was removed at this stage. Table 3 details quality ratings and characteristics of the twelve included studies in this review.

**Table 3.** Quality ratings and characteristics of included studies.

| Study and Quality Rating | Study Aim | Participants | Measures | Intervention Session Duration | Intervention Design | Findings |
|---|---|---|---|---|---|---|
| **Structured stimulation intervention** | | | | | | |
| Lancioni et al. 2006<br><br>MODERATE | 1. Assess effects of stimulation and microswitch- based interventions on indices of happiness<br><br>2. Compare effects of both interventions | n total participants= 7<br>n participants ≥ age 16 =3 (age 16-20)<br><br>-3 Participants profound intellectual disability;<br>-3 Visual difficulties;<br>-2 Non-ambulatory;<br>-1 Epilepsy & meds | 1.Indices of happiness (smiling, laughing, excited vocalisation with or without arm movements)<br><br>2.Selection of preferred stimuli Stimulus preference screening | 10 mins | *ABAC & alternating treatments design*<br>1. Phase 1 (stimulation intervention)<br>44-50 sessions<br>2. Phase 2 (microswitch intervention)<br>34-38 sessions<br>3. Phase 3 (Both interventions)<br>35-55 sessions per intervention | 1. Both interventions increased indices of happiness compared with baseline<br><br>2. Greater effect of microswitch compared to stimulation intervention for 1 participant |
| Darling & Circo 2015<br><br>MODERATE | 1. Assess effects of presentation of preferred items over multiple periods of the day on indices of happiness | n total participants= 3 (age 30-57)<br><br>- 3 Profound intellectual disability;<br>-1 Visual difficulties;<br>-2 Non-ambulatory;<br>-2 Hearing impairments;<br>-2 Seizure disorder | 1. Indices of happiness (smiling, laughing, engaging in specific activities at higher rate in comparison to when engaging in less preferred activities)<br><br>2.Selection of preferred stimuli RAISD caregiver structured interview | 10 mins | *Multiple baseline design*<br>1. Phase 1<br>7-12 sessions | 1. Small increase in indices of happiness for all 3 participants during intervention phase compared to baseline |

| Favourite stimulation automatically delivered on exercise engagement | | | | | | |
|---|---|---|---|---|---|---|
| Lancioni et al. 2007a<br><br>MODERATE | 1. Assess effects of contingent stimulation on frequency of steps<br><br>2. Monitor indices of happiness | Study II<br>n participants= 2<br>(age 19-41)<br><br>-2 Participants profound intellectual disability;<br>-1 Visual difficulties;<br>-1 Epilepsy & meds | 1.Indices of happiness (smiling, excited vocalisations)<br><br>2.Selection of preferred stimuli<br>Stimulus preference screening | 5 mins | *ABAB*<br>1. Phase 1<br> 33-52 sessions<br>2. Phase 2<br>50-60 sessions | 1. Increased indices of happiness during intervention compared to baseline |
| Lancioni et al. 2012<br><br>MODERATE | 1. Assess effects of contingent stimulation on walking fluency<br><br>2. Monitor indices of happiness | Study I<br>n participants= 1<br>(age 25)<br><br>-Profound intellectual disability;<br>-Visual difficulties | 1. Indices of happiness (smiling, laughing, excited vocalisations)<br><br>2. Selection of preferred stimuli<br>Parents and staff recommendations and brief stimulus preference screening | 1 session= 5 travels of between 8-16m | *ABAB*<br>1. Phase 1<br>15 sessions<br>2. Phase 2<br>82 sessions | 1. Increased indices of happiness during intervention compared to baseline |
| Lancioni et al. 2013b<br><br>MODERATE | 1. Assess effects of contingent stimulation on right and left foot leg responses<br><br>2. Monitor indices of positive involvement | n participants= 3<br>(age 22-42)<br><br>-3 Profound intellectual disability;<br>-3 Visual difficulties;<br>-3 Non-ambulatory;<br>-1 Hearing impairment;<br>-1 Epilepsy & meds | 1. Indices of positive involvement (smiling, music related movement of hands/head, vocalisations, touching vibratory devices).<br><br> 2.Selection of preferred stimuli<br>Stimulus preference screening | 10 mins (2 participants);<br>5 mins (1 participant) | *Multiple probe across responses design*<br>1. Phase 1 (either right or left foot response)<br>42-61 sessions<br>2. Phase 2 (other response not targeted in phase 1)<br>43-52 sessions<br>3. Phase 3 (alternating responses)<br>37-66 sessions<br>4. Follow up (alternating responses)<br>20 sessions | 1. Increased indices of positive involvement for all 3 participants during intervention compared to baseline. |

| Lancioni et al. 2013c

MODERATE | 1. Assess effects of contingent stimulation on enhancing ambulation performance

2. Monitor indices of happiness | Study III
n participants= 1
(age 34)

-Severe- profound intellectual disability;
-Visual difficulties | 1. Indices of happiness (smiling, excited vocalisations)

2.Selection of preferred stimuli
Stimulus preference screening | 1min | *ABAB*
1. Phase 1
290 sessions
2. Phase
 873 sessions | 1. Increased indices of happiness with intervention in comparison to baseline |
|---|---|---|---|---|---|---|
| Stasolla & Caffo 2013

MODERATE | 1. Assess effects of contingent stimulation on promoting object manipulation and ambulation fluency

2. Monitor indices of happiness | n participants= 2
n participants ≥ age 16 =1
(age 17)

-Severe- profound intellectual disability;
-Epilepsy | 1. Indices of happiness (smiling, laughing, excited body movements with or without vocalisations)

2.Selection of preferred stimuli
Parent interviews and preference screening using suggestions | 5 mins | *Multiple probe design across behaviours*
1. Phase 1 (object manipulation response)
50 sessions
2. Phase 2 (ambulation response)
50 sessions
3. Phase 3 (alternating responses)
40 sessions | 1. Increased indices of happiness during intervention phases in comparison to baseline |
| Stasolla et al. 2018

GOOD | 1. Assessing contingency awareness and promoting locomotion fluency

2. Monitor indices of happiness | n participants= 5
n participants ≥ age 16 =2
(age 16-17)

-2 Severe- profound intellectual disability;
-2 Seizure disorder | 1. Indices of happiness (smiling, laughing, excited and energised body arm and leg movements with or without vocalisations)

2.Selection of preferred stimuli
Informal parent and caregiver interview and screening preference assessment. | 5 mins | *ABABCBCB*
1. Phase 1 (contingent stimulation phase)
40 sessions
2. Phase 2 (contingent)
40 sessions
3. Phase 3 (non-contingent stimulation phase)
20 sessions
4. Phase 4 (contingent)
30 sessions
5. Phase 5 (non-contingent)
20 sessions
6. Phase 6 (contingent)
30 sessions | 1. Increased indices of happiness during contingent phases compared to baseline and non-contingent phases. |

**Microswitch-based stimulation intervention**

| | | | | | | |
|---|---|---|---|---|---|---|
| Lancioni et al. 2007b<br><br>MODERATE | 1. Evaluate effects of microswitch-based intervention on indices of happiness | n total participants= 9<br>n participants ≥ age 16 =1 (age 18)<br><br>-Severe-profound intellectual disability;<br>-Visual difficulties;<br>-Extensive motor impairment;<br>-Epilepsy & meds | <u>1. Indices of happiness</u> (smiling, laughing with open mouth, excited vocalisation with or without body movements)<br><u>2.Selection of preferred stimuli</u><br>Stimulus preference screening | 10 mins | *ABAB*<br><u>1. Phase 1</u><br>51 sessions<br><u>2. Phase</u><br>56 sessions | 1. Increased indices of happiness during intervention in comparison to baseline |
| Lancioni et al. 2007c<br><br>MODERATE | 1. Assess use of microswitch intervention with person with deteriorating motor condition<br><br>2. Monitor indices of happiness | n participant =1 (age 17)<br><br>-Profound intellectual disability;<br>-Visual difficulties;<br>-Non-ambulatory;<br>-Epilepsy | <u>1. Indices of happiness</u> (smiling)<br><br><u>2.Selection of preferred stimuli</u><br>Parents and staff recommendations and brief stimulus preference screening | 5 mins | *Multiple probe across responses*<br><u>1. Phase 1</u> (eye & mouth responses separately)<br>73-96 sessions<br><u>2. Phase 2</u> (alternating responses)<br>10-12 sessions<br><u>3. Phase 3</u> (both responses)<br>84 sessions<br><u>4. Follow up</u> (both responses)<br>21 sessions | 1. Increased indices of happiness during intervention phases in comparison to baseline |
| Lancioni et al. 2011<br><br>MODERATE | 1. Monitor performance of stimulus choice and continuation/repetition requests using microswitch<br>2. Monitor indices of happiness | n participants= 2 (age 31-34)<br><br>-2 Profound intellectual disability;<br>-2 Visual difficulties;<br>-2 Non-ambulatory | <u>1. Indices of happiness</u> (smiling, laughing, excited vocalisations)<br><u>2.Selection of preferred stimuli</u><br>Staff interviews and brief stimulus preference screening | Sessions lasted until 18 stimuli were presented or 60mins elapsed | *Multiple baseline design*<br><u>1. Phase 1</u><br>129-304 sessions | 1. Increased indices of happiness during intervention compared to non-engagement periods |

| Lancioni et al. 2014  MODERATE | 1. Assess use of microswitch in using more flexible responses (such as left or right movements)  2. Monitor indices of happiness | n total participants= 2  (age 16-21)  -2 Severe-Profound intellectual disability; -2 Non-ambulatory -1 Seizure disorder & meds -1 Epilepsy | 1.Indices of happiness (smiles, excited vocalisations)  2.Selection of preferred stimuli Stimulus preference screening | 5 mins | *ABAB* 1. Phase 1 50-88 sessions 2. Phase 2 91-273 sessions 3. Follow up 20 sessions | 1. Increased indices of happiness with intervention compared to baseline |
|---|---|---|---|---|---|---|

*Participant characteristics*

There were 22 participants in total included in this review. The age range of participants was between 16- 57, and included 13 men and 9 women. Five of the included studies gave no information about the method of participant recruitment (Lancioni et al., 2006; 2007a; 2013b; 2014; Stasolla et al., 2018), and none of the studies described the study location. Only one study used a formal assessment (The Vineland Adaptive Behaviour Scale Second Edition; Sparrow et al., 2005) to confirm that participants had a severe or profound intellectual disability (Stasolla et al., 2018).

*Research design*

Ten of the studies recruited new samples of participants, while 3 of the studies did not report this information, and may have used the same individuals who took part in previous experiments (Darling & Circo, 2015; Lancioni et al., 2012; 2013b). A variety of single-case experimental designs were used: (i) eight studies used withdrawal designs, and (ii) five studies used multiple baseline designs, with one adopting a non-concurrent method, and three using multiple probe designs.

Three studies reported less than 5 sessions during baseline phases (Lancioni et al., 2007a; 2012; 2013b). Five data points per experimental phase is recommended to be able to reliably demonstrate intervention effects (Tate et al., 2013).

*Indices of happiness*

There were variations in the operational definitions of 'indices of happiness' used: (i) smiling; (ii) excited vocalisation with/without body movements; (iii) laughing/ laughing with open mouth; (iv) excited and energised body movements, with/without vocalisations, and (v) engaging in preferred activities at a higher rate than other activities. One study used 'indices

of positive involvement' defined as smiling, music related movement of hands/head, vocalisations and touching vibratory devices. Three studies reported using idiosyncratic indices of happiness collected from observations and information gained from carers who were thought to have insight into how the participants typically express themselves (Darling & Circo, 2015; Lancioni et al., 2007b; 2007c).

Indices of happiness were recorded according to a partial interval recording system. Inter-observer agreement was assessed for at least 20% of the data, with a minimum mean percentage agreement of 90% in all studies. Three studies reported the range of inter-observer agreement as 70-100% (Lancioni et al., 2007a; 2007c; 2013b) and 60-100% for another study (Lancioni et al., 2006). Tate et al. (2013) suggests that 80% constitutes a general guideline for a minimally acceptable inter-observer agreement.

### *Preferred stimuli*

Preferred stimuli were assessed using a variety of methods: (i) six studies used stimulus preference screening (Green et al., 1988). This involves repeatedly presenting a variety of stimuli to an individual and measuring positive reactions such as smiling or approach behaviours, to differentiate preferred from non-preferred stimuli; (ii) five studies used parents' and staff recommendations to inform subsequent stimulus preference screening, and (iii) one study used the Reinforcer Assessment for Individuals with Severe Disabilities (RAISD; Fisher et al., 1996). This is a structured interview for caregivers to identify information about reinforcers for an individual.

*Findings*

Results for each intervention method are considered separately. As presented in Table 3, two studies used a structured stimulation intervention (Lancioni et al., 2006; Darling & Circo, 2015), six studies used favourite stimulation, automatically delivered on exercise engagement (Lancioni, et al., 2007a; 2012; 2013b; 2013c; Stasolla, et al., 2013; 2018), and four studies used microswitch-based stimulation interventions (Lancioni et al., 2007b; 2007c; 2011; 2014).

*Structured stimulation intervention*

As detailed in Table 3, Lancioni et al. (2006) assessed the effects of a structured stimulation intervention in comparison to a microswitch intervention on indices of happiness. Favourite stimuli were identified using stimulus preference screening, which involved displaying various items in front of the participants a number of times, and choosing stimuli that individuals had positive reactions to, in the majority of the presentations. The structured stimulation intervention involved presenting participants with 4-6 of their favourite stimuli, such as music, vibratory input, and light displays, in rotation for 1.5 minutes each during every 10 minute intervention session. The microswitch intervention involved participants using hand pushing or elbow backward movements to activate a microswitch, which turned on the above mentioned favourite stimuli for 6-9 seconds. Results indicated that both interventions were effective in increasing indices of happiness, such as smiling and laughing, with one participant showing a greater increase in happiness indices with the microswitch intervention compared to structured stimulation.

Darling and Circo (2015) used a similar stimulation intervention to determine if exposing participants to their preferred items or activities during multiple periods of the day resulted in increased indices of happiness. Preferred items were selected by individuals who

had known the participant for 7-34 months, using the Reinforcer Assessment for Individuals with Severe Disabilities (RAISD). Only small increases in indices of happiness were found during the intervention, when preferred items were presented in comparison to baseline, with a large variation in indices of happiness scores within the intervention phase. This study received a moderate quality rating. Staff received training before implementing the intervention and fidelity checks were carried out to ensure adherence to agreed procedures. However, one of the three participants did not complete the study.

*Favourite stimulation automatically delivered on exercise engagement*

Research undertaken by Lancioni et al. (2007a) and Lancioni et al. (2013c) assessed the effects of reinforcers delivered when participants took a step forward. Both studies used similar methods and obtained moderate quality ratings. Favourite stimuli were ascertained by stimulus preference screening, and included music, songs, and encouraging messages. Participants took more steps and demonstrated higher levels of indices of happiness when preferred stimuli were delivered in comparison to baseline. However in Lancioni et al.'s (2013c) study, which used an ABAB withdrawal design, increased indices of happiness were also apparent initially in the second baseline phase, which makes changes during the intervention phase difficult to interpret. This may represent an intervention 'carry-over' effect, where changes in behaviour endure post intervention.

Lancioni et al. (2012) similarly used preferred stimuli to improve walking fluency of an individual who tended to take breaks when travelling from one destination to another. During intervention, the participant received preferred music at intervals of 1.5-2m along their travel route. Behavioural indicators of happiness, including smiling and laughing, increased during intervention, as did the participants' ability to walk without breaks. Another study included three non- ambulatory adults with profound intellectual disabilities, and aimed

to increase their foot and leg movements (Lancioni et al., 2013b). Indices of positive

involvement were used as a means to assess the effects of this intervention, such as smiling,

and music related movement of hands or head. In line with previous studies, increased indices

of positive involvement and foot and leg movement were found during intervention when

preferred stimuli were paired with exercise.

Stasolla et al. (2013) examined whether preferred lights and music given to an

individual, on completion of 4 steps in a 3 second interval, enhanced fluency of walking and

happiness levels. Indices of happiness such as smiling and laughing and walking fluency

increased during the intervention. Stasolla et al. (2018) conducted a similar study, but had a

number of additional methodological strengths, including blinding of assessors. They also

presented a full set of results, instead of aggregated data, and was the only study to receive a

strong quality rating. This study aimed to assess whether differences in intervention outcomes

(indices of happiness and walking fluency) were due to the availability of favourite stimuli or

its connection with walking responses. Further information about the study design is

available in Table 3. Higher levels of indices of happiness and walking fluency were found

when preferred stimuli were delivered in response to participant steps, in comparison to when

preferred stimuli were available continuously, irrespective of performance of steps. This

study also included a social validation assessment in which parents and caregivers rated

participants as enjoying the contingent intervention phase more than the non-contingent

phase.


*Microswitch-based stimulation intervention*

Lancioni et al. (2007b) evaluated the effects of a microswitch intervention on indices of

happiness for one participant, and received a moderate study quality rating. A stimulus

preference screening method was used to identify preferred stimuli. The participant used a

head-turning response for microswitch activation. During intervention, the head-turning

response turned on preferred songs, lights and vibratory input for 6-9 seconds. As detailed in

Table 3, increased indices of happiness were found during the intervention when compared to

baseline. Lancioni et al. (2014) conducted another study where flexible head and hand

movements by the participant activated the microswitch. Once again, greater indices of

happiness were found during the intervention compared to baseline.

Lancioni et al. (2007c) conducted a microswitch intervention with a participant with

very minimal motor movement. The responses used to activate the microswitch in this study

were eye and mouth opening. During the intervention, preferred music and vibratory input,

were delivered following participants' microswitch responses. Increased behavioural

indicators of happiness, such as smiling, were found during the intervention phase in

comparison to baseline. In another study, Lancioni et al. (2011) used a more elaborate

microswitch technology to enable individuals to choose their preferred stimuli. This involved

a computer system presenting voice samples of preferred and non-preferred stimuli to

participants for 5 seconds, including parts of songs or familiar voices or stories. Participants

used partial closure of their right or left hand to activate a microswitch device, which allowed

them to choose between the samples of stimuli, and activate their preferred stimulus for 20

seconds. Participants appeared to be successful in selecting their preferred stimuli. Increased

indices of happiness were found during intervention, in which preferred stimuli were

presented for 20 seconds, in comparison to non-engagement periods, when participants did

not receive any stimulation.

## Discussion

This systematic review of the literature concerned interventions designed to increase indices of happiness in individuals with severe or profound intellectual disabilities, carried out in the last twelve years. It is worth noting that the results of the studies included in this review were all based on single subjects, and all studies had relatively weak study designs. However despite this, research using favourite stimulation automatically delivered on exercise engagement and microswitch-based intervention methods found a consistent increase in participant's indices of happiness. These results are largely similar to Lancioni, et al. (2005a) and Dillon & Carr's (2007) reviews, which found increased happiness indices for participants exposed to both exercise engagement and microswitch interventions.

There was less evidence for structured stimulation as an intervention to improve mood in this review. Darling and Circo (2015) found minimal increases in indices of happiness when participants took part in a structured stimulation intervention. These results appear to be in contrast with previous reviews, which pointed to positive findings when using structured stimulation to increase participants' indices of happiness (Lancioni, et al., 2005a; Dillon & Carr, 2007). There appears to be a move away from using structured stimulation as an intervention method to improve mood, with two studies included in the current review, whereas eight studies used this intervention in Lancioni et al.'s (2005a) review.

### *Methodological limitations and future research*

Darling and Circo's (2015) findings may have been affected by the study methodology used to identify their participant's favourite stimuli. The Reinforcer Assessment for Individuals with Severe Disabilities (RAISD) structured interview was used in this study. The RAISD seeks to identify preferred stimuli using carer reporting. There is contrasting evidence about

the accuracy of caregivers in identifying individuals' preferences (Green, Gardner, & Reid, 1997; Ivancic et al., 1997).

Darling and Circo (2015) also questioned whether the behavioural indices used in their study failed to capture changes in their participant's mood. This has been suggested in other research, particularly with individuals with minimal movement whose behavioural changes may be very subtle and difficult to detect (Ivancic et al., 1997). Less conventional behavioural indicators of affect have been suggested, such as changes in eye opening, or using electrophysiological indicators of mood, such as heart rate and respiratory rhythm (Lancioni et al., 2005a; McManis et al., 2001; Shapiro et al., 1997). However, the technology used to assess electrophysiological data may not be suitable to use with individuals with additional physical health difficulties (Flynn et al., 2017). It is also noteworthy that only three studies included in this review reported using idiosyncratic indices of happiness, collected from observations and information gained from carers who know the individual well, and how they may typically express their emotional state. In addition, happiness as a construct refers to an internal, subjective state and caution is needed when inferring internal states from overt, observable behaviours such as smiling or laughing. One criticism is that individuals may be smiling for social or operant reasons, which may occur when an individual is not happy. However, this is thought to be less likely for people with severe or profound intellectual disabilities who typically engage in fewer behaviours under apparent social control (Green & Reid, 1996).

Limitations of the existing research base include reliance on single-case methods and on a small number of sessions to demonstrate intervention effects, making it difficult to reliably interpret if changes in indices of happiness were due to the interventions. Given the difficulty in recruiting larger numbers of participants with significant impairments into a research trial, one approach to obtaining more robust evidence may be to conduct a synthesis

of the available studies' results. Raw data can provide a common measure for the purpose of collating data across multiple single-case studies and can help to build an evidence base via meta- analysis. However, raw data was only provided by one study included in this review. A meta-analysis could help to achieve Tate et al.'s (2016) proposal, that a strong basis for causal interference can be made, when an intervention effect is replicated with at least twenty participants, by a minimum of five methodically strong research reports, and conducted by at least three different research teams.

A limitation of this review was that nine out of the twelve included studies were by the same author. Therefore caution needs to be taken when interpreting the validity of these results, as it may be possible that a feature of their approach could have systematically biased results. Research studies prior to 2006 were not included in this review, and therefore additional potential intervention methods for increasing mood in this population published within this timeframe were not considered, such as positive behaviour support programmes or mindful caregiving approaches. In addition, the studies included in this review did not include data from children with severe or profound intellectual disabilities and results are limited to adult studies.

### *Clinical Implications*

The interventions included in this review had beneficial effects on participant's indices of happiness, and represent opportunities to improve the mood and quality of life of individuals with severe and profound intellectual disabilities. Microswitch interventions offer the potential to afford individuals with severe or profound intellectual disabilities more control over their lives and the opportunity to make choices. In this regard, microswitch interventions may be viewed as preferable to structured stimulation interventions in terms of increasing individuals' indices of happiness. In addition, interventions delivering favourite stimuli in

response to exercise engagement may offer additional motor and health benefits for individuals. It may also be possible for the intervention methods described in this study to be adapted to measure indices of happiness during the course of a day, or a longer time period to help establish the activities an individual enjoys. This information could be used clinically to increase the number of enjoyable activities for an individual, which may help to improve mood and promote wellbeing.

### *Conclusion*

This review has highlighted the potential benefits of microswitch interventions and preferred stimuli delivered in response to exercise engagement, in improving mood in individuals with severe or profound intellectual disabilities. Future research is needed to ascertain the degree to which using restricted behavioural indices and different methodologies to assess preferred stimuli affect an intervention's efficacy.

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# CHAPTER TWO: MAJOR RESEARCH PROJECT

*Listening to Mothers: Experiences of Mental Health Support and Insights into Adapting Therapy for People with Severe or Profound Intellectual Disabilities.*

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Prepared in accordance with authors instructions for the Journal of Applied Research in Intellectual Disabilities (JARID) (see Appendix 2.1)

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## Plain English Summary

**Background:** There is some evidence to suggest that individuals with severe and profound intellectual disabilities may be more likely to experience mental health problems. However, people may find it difficult to obtain treatment, and very little is known about effective psychological therapies for these individuals.

**Aims:** This study aimed to explore mothers' experiences of seeking mental health support for their sons and daughters with severe or profound intellectual disabilities and emotional difficulties. Mothers' views about ways of adapting psychological therapy to make it more accessible for these individuals were also examined.

**Methods:** Six mothers of adults with severe or profound intellectual disabilities, who had tried to access mental health support for their son or daughter's emotional difficulties, were interviewed about their experiences. Interviews were audio-recorded, and analysed using Interpretative Phenomenological Analysis.

**Results:** Mothers said that it was difficult to identify symptoms of poor emotional wellbeing in their offspring. There were also barriers to individuals getting adequate mental health support, with professionals thought to lack the knowledge and skills to work with people with more severe intellectual disabilities, resulting in individuals being discriminated against. Mothers described the importance of therapists spending time getting to know the individual to aid communication, and the essential role carers can play in therapy. The therapeutic relationship was considered particularly important in facilitating engagement in therapy.

**Conclusion:** This study highlights the need for more appropriate and sensitive mental health support for individuals with severe and profound intellectual disabilities. These findings have clinical relevance and could support future research in establishing the effectiveness of psychological therapies for people with severe or profound intellectual disabilities.

## Abstract

**Background:** Individuals with severe or profound intellectual disabilities can face difficulties in getting mental health support, and little is known about psychological therapies for this population. Mothers' experiences and perspectives in seeking support and adapting therapies were explored.

**Method:** Semi-structured interviews were conducted with six mothers of adults with severe or profound intellectual disabilities, who had sought mental health support for their offspring. Interviews were audio-recorded, and analysed using Interpretative Phenomenological Analysis.

**Results:** Mothers found it difficult to recognise signs of emotional difficulties in their offspring. Individuals faced barriers to receiving adequate support, with professionals thought to lack the knowledge to work with people with severe impairments, resulting in individuals facing discrimination. The importance of the therapeutic relationship and involving carers in therapy were considered.

**Conclusion:** This study highlights the need for more appropriate mental health support for these individuals. Future research could trial adapted psychological therapies with this population.

**Key words:** intellectual disability, mental health, support, therapy

**Introduction**

There is evidence to suggest that individuals with intellectual disabilities are more likely to experience mental health difficulties than the general population, with a prevalence rate of 40.9% for adults (Cooper et al., 2007). Within the intellectual disability population, individuals with severe or profound disabilities may be at an even greater risk of developing mental ill health (Cooper et al., 2007). Some of the reasons for this increased risk may include experiencing additional physical disabilities and health problems, having less access to purposeful day time activities (Jones et al., 1999), and experiencing a poorer quality of life (Perry & Felce, 2003).

Despite this increased mental health need amongst people with a severe or profound intellectual disability, individuals face a number of obstacles to getting appropriate support. Individuals are unable to self-report, with distress often expressed through behaviour such as changes in facial expression, vocalisations, self-injurious behaviour and becoming more withdrawn (The Foundation for People with Learning Disabilities, 2005). Carers may not recognise these behaviours as an indication of poor emotional wellbeing and diagnostic overshadowing may occur, whereby presenting problems are ascribed to an individual's intellectual disability rather than recognised as a mental health problem (Carr et al., 2016). There can also be a lack of knowledge in relation to recognising emotional difficulties. Care staff, who are often responsible for deciding whether or not to initiate referrals to mental health services, may also lack the knowledge or understanding to recognise emotional difficulties (Bates, Priest & Gibbs, 2004). In addition, many diagnostic measures used in clinical practice rely on proxy reports of ratings of behaviour, and it is possible that mental health problems may not be reliably identified, instead being attributed to other causes such as a behavioural problem, or to the person's intellectual disability (Flynn et al., 2017).

It has also been recognised that there are inequalities in the way people with intellectual disabilities are supported by health and social care services (The Scottish Government, 2012; 2013). Individuals with severe and profound intellectual disabilities may face even greater challenges in getting adequate support. Raising Our Sights (Mansell, 2010), a report of the service needs of adults with severe and profound intellectual disability, described individuals experiencing discrimination in accessing health and social care services, such as professionals viewing individuals as being 'too disabled' to be able to work with. Some staff also appeared to have low expectations of what is possible to achieve with those who have a severe and profound intellectual disability.

Research has shown that people with profound intellectual disabilities can face similar difficulties when accessing mental health support in particular (Chinn & Abraham, 2016; The Foundation for People with Learning Disabilities, 2014). Little is known, however, about carer experiences of seeking support for individuals with severe or profound intellectual disabilities and emotional difficulties. It would appear that only one qualitative research study has explored service support available to family carers and paid care staff for the mental health of young people with profound intellectual disabilities (Phillip, Lambe & Hogg, 2005). Family carers felt that there was no professional support or advice available to help their children's emotional difficulties, with no dedicated or qualified professionals with specialist knowledge in severe and profound intellectual disabilities. In contrast, paid care staff highlighted that whilst psychological and psychiatric advice was available to them, they felt that the most helpful strategies were suggested by people that knew the individual well, with professionals often not having the time to devise appropriate interventions due to workload. In addition, care staff thought that professionals lack the ability to deal with the significant communication problems of individuals with severe or profound intellectual disabilities (Phillip, Lambe & Hogg, 2005).

There are few evidence-based psychosocial interventions adapted to address the mental health problems of individuals with intellectual disabilities (The British Psychological Society, 2016; The Scottish Government, 2015), with medication as the most commonly used treatment option (Carr, 2016). Even less is known about effective psychological interventions for people with more severe intellectual disabilities, and the National Institute for Health and Care Excellence (NICE) has published guidelines recommending additional research in this area (NICE, 2016). Existing psychological therapy provision is not accessible for individuals with more significant impairments due to excessive cognitive and communicative demands, and there is a need for alternative methods of support to be developed.

There is limited knowledge about mental health in people with severe or profound intellectual disabilities, and how psychological interventions might be adapted for this population. Therefore, insights from people who care for individuals with severe or profound intellectual disabilities may provide invaluable information in this regard. This study aimed to examine the lived experience of mothers in seeking support for their offspring with severe or profound intellectual disabilities and emotional difficulties. It also sought mothers' views about making psychological interventions more accessible for individuals with a severe or profound intellectual disability.

**Method**

*Design*

This qualitative study used Interpretative Phenomenological Analysis (IPA) to explore the views of mothers of individuals with severe or profound intellectual disabilities. IPA is theoretically underpinned by phenomenology, hermeneutics and idiography, and is an approach concerned with making sense of an individual's subjective experiences. It involves the researcher attempting to interpret and understand participants' perspectives of certain events in their lives (Smith, Flowers & Larkin, 2009).

*Participants*

Purposive, homogeneous sampling was used in this study (Smith, Flowers & Larkin, 2009). Seven mothers were recruited from PAMIS, a voluntary organisation for individuals with profound and multiple intellectual disabilities and their families. They were all mothers of an individual over the age of 18 with a diagnosis of a severe or profound intellectual disability, and had experience of seeking support for mental health difficulties faced by the individual. One participant's interview was not included in the analysis stage of this research, as her daughter died, and it was therefore thought that this participant's views would introduce too much heterogeneity within the sample experience.

      Four of the participants were biological mothers and one had been the adoptive mother to two daughters with severe and profound intellectual disabilities since they were infants (*Bernadette). The final participant had been the primary carer of an individual for the past five years (Joanne). She had taken on a maternal role and had become the main carer for this person in her own home. The term 'mothers' was used to refer to all participants in this study. The mothers lived with partners, and four participants' offspring lived at home with them, with two individuals residing in supported accommodation. Four participants' offspring

attended day services part time, with one participant's daughter unable to leave her home due to physical health difficulties (Hayley). All mothers described seeking support for their offspring's anxiety or depression symptoms. Participant and offspring demographic information is provided in Table 1. Information is not presented for the participant excluded from the analysis stage of this research.

**Table 1.** Participant and offspring demographic information

| Participant Name | Son/ Daughter Name | Son/ Daughter Age | Level of Intellectual disability |
|---|---|---|---|
| Angela | Sarah | 29 | Profound |
| Sinead | Claire | 21 | Profound |
| Maureen | Hayley | 30 | Profound |
| Breda | Mark | 39 | Severe |
| Bernadette | Mary | 24 | Severe |
| Bernadette | Paula | 20 | Profound |
| Joanne | Colin | 21 | Profound |

 *All names provided are pseudonyms.

### *Semi-structured interview*

One-to-one semi-structured interviews were conducted using a topic guide. An exploratory stance was taken by the researcher, asking open-ended questions to enable participants to talk freely and reflectively, with the aim of obtaining rich narratives. The following are examples of open-ended questions asked: "Was there a time when you thought your son or daughter had an emotional difficulty?"; "Can you tell me about your experience of getting support?"; "What was helpful/ unhelpful in the treatment of your son or daughter's emotional difficulties?". The topic guide (Appendix 2.2) was developed with reference to the literature base and in discussion with the research team. It was also co-constructed with a group of mothers with children and adolescents with profound and multiple intellectual disabilities who were involved with PAMIS, to ensure the relevance of interview topics. The topic guide

also contained specific open-ended questions relating to adapting behavioural activation therapy for individuals with severe or profound intellectual disabilities. Prior to the interviews the researcher aimed to put participants at ease. Due to the emotive nature of the discussion, participants were told that they could take a break or stop the interview at any point.

### *Procedure*

Information was provided to PAMIS as to the purpose of the study. PAMIS then identified carers that met the eligibility criteria. PAMIS staff members provided potential participants with the study information sheet (Appendix 2.3). If interested, participants gave verbal consent to PAMIS staff for their contact details to be passed to the researcher to discuss the study further, and obtain consent if they wished to proceed. An additional recruitment procedure was also used, involving PAMIS providing information about the study on their online Facebook page. Interested participants were invited to contact PAMIS or the researcher directly. On deciding that they wanted to take part in the study, an information sheet about behavioural activation therapy was sent to participants (Appendix 2.4), so that mothers were familiar with the therapy informing some of the discussion during interviews. Three interviews were conducted face-to-face by the researcher within PAMIS offices or public buildings used by PAMIS, and three interviews were conducted over the telephone, for the convenience of carers. Telephone interviews have been found to generate similar quality data to traditional face-to-face interview methods (Braun & Clarke, 2013). Interviews lasted between 50 and 98 minutes.

*Data Analysis*

Interviews were audio recorded, transcribed verbatim with patient identifying information removed, and pseudonyms assigned instead. In line with Smith, Flowers & Larkin's (2009) recommendations, each transcript was read and re-read, and the audio recordings listened to. A detailed set of notes were then created focusing on descriptive, linguistic and conceptual interpretation of the data (Appendix 2.5). The next stage in analysis comprised of analysing the initial notes to identify emergent themes, involving producing concise and meaningful statements that capture the essence of the various comments attached to the transcript (Appendix 2.5). Patterns and connections between emergent themes were then identified, and superordinate themes were created offering a higher order organising device. Once each transcript had been analysed, patterns were looked for across participant interviews.

A number of steps were taken to ensure rigour and quality during the analysis process. A member of the research team read two transcripts and associated emergent themes, and possible interpretations were discussed. In addition, a research diary was used to support the bracketing of the researcher's preconceptions, and to capture the decision making process during the bringing together of themes. The researcher also produced a summary of each interview to ensure the emergent themes were grounded in the overall experiences of each participant, as well as reflecting the experiences across the sample as a whole.

The specific set of questions relating to adapting behavioural activation therapy were not in keeping with the data collected about the mothers' experience of seeking emotional support for their offspring and their views about the support their offspring required. Consequently, whilst the mothers' more general views about the need to adapt psychological therapies for their offspring were included in the analyses, the data from the specific questions regarding the adaptation of behavioural activation will be reported elsewhere. A brief overview of these findings is provided in Appendix 2.6.

*Ethical considerations*

This study was approved by the College of Medical, Veterinary and Life Sciences, University of Glasgow Ethics Committee. Informed consent was obtained for all participants before commencing the interviews. For interviews conducted over the telephone, verbal consent was sought and participants were asked to sign and return a consent form via post (Appendix 2.7). All participants consented to the use of anonymised quotes.

*Researcher Reflexivity*

The researcher was a trainee clinical psychologist, having worked clinically with individuals with intellectual disabilities and with personal experience with a family member with an intellectual disability, which provided an awareness of the challenges discussed by participants.  The researcher engaged in reflective practice using a diary in order to reduce the impact of one's preconceptions on interpretation. Through this reflective process the researcher noticed for example, that the researcher's initial conceptualisation of mental health problems reflected that of 'classic' presentations, in which symptoms manifest in 'typical' ways and causal factors can be established. The reflective diary also allowed the researcher to reflect on their emotional responses to mothers' interviews. The researcher was struck by the strength and tenacity of mothers in supporting their offspring to the best of their ability in very difficult circumstances. In addition, the researcher was moved by the failure of services in acknowledging and meeting individuals' needs.

# Results

Analysis produced three superordinate themes and eight related subordinate themes, as shown

in Table 2.

**Table 2.** Superordinate and subordinate themes

| Superordinate | Subordinate |
|---|---|
| A struggle for understanding | Emotional difficulties as a hidden problem |
| | Trying to make sense of the problem |
| | Emotional consequences |
| | |
| Challenges to getting mental health support | Concerns not taken seriously |
| | No support available |
| | Lack of expertise |
| | Individuals discriminated against |
| | |
| A mother's approach to adapting therapy | Taking time to get to know each other |

**A struggle for understanding**

*Emotional difficulties as a hidden problem*

Some mothers had difficulty recognising behavioural indicators signifying a change in their

offspring's emotional wellbeing, with Joanne suggesting that it was only through prior

experience of her own son's emotional difficulties that she had become aware of the signs

with her adopted son. It appeared that mothers were sometimes frustrated at care staff for

misunderstanding behavioural indicators of emotional difficulties in their offspring, and

misattributing these indicators to their intellectual disability or a physical health problem.

However, some mothers also struggled to recognise signs of distress, as was apparent from

Angela's attempt to understand her daughter's behaviour when her Gran died:

In participant quotations, (…) indicates that some text has been omitted, with [ ] representing words inserted for
clarity. Participant name, transcript number and transcript line number are also given.

*"....She would have suffered the loss of her gran at the time and must have been, she must have been distressed and she must have been anxious and wondering where is where is gran, but she must have, she must have experienced that loss in some way, which wouldn't necessarily manifest itself in a way that we understood."* (Angela, 1.230)

Angela also said that her daughter did not demonstrate distinctive behavioural signs associated with a particular emotion, and as a result it was hard to differentiate between her daughter's behavioural expressions of anxiety and sadness.

*Trying to make sense of the problem*

When mothers did recognise that their offspring were distressed, they found it difficult to know what had caused their upset, as their son or daughter could not tell them. Maureen described her struggle to make sense of her daughter's distress:

*"I'm not really sure if it is something to do with the carers or if it is depression. I'm pretty sure it is depression because she shouts on [brother's name that passed away] all the time but there is also the fact that there is no stimulation for her there during the day either (pause) so is it just that she's being left alone so she just wants left alone do you know what I mean. We're in that bit ehh where is it this or is it that"* (Maureen, 4.425)

This quote illustrates Maureen's confusion in trying to understand her daughter Hayley's upset. Mothers compared making sense of their offspring's distress to a problem solving exercise, in which potential causes are considered, and a number of different solutions are tried out to resolve the difficulty.

*Emotional consequences*

Some parents expressed sadness at wanting to be able to help their child when in distress, but feeling powerless at being able to do so. Angela described the natural inclination she feels as a mother to want to relieve her child of discomfort but at the same time being unable to understand what is causing her daughter's difficulties. Another mother, Maureen, felt a sense of impotence at being unable to help her child:

*"At the time you start getting down yourself because you feel that you can't help really so it actually starts getting you down because you feel that you've failed you know trying to help her (pause)"* (Maureen, 4.349)


This extract demonstrates the emotional impact on Maureen. Throughout the interviews, it was apparent that this was an emotive and difficult topic for mothers to discuss.


**Challenges to getting mental health support**

*Concerns not taken seriously*

Some mothers highlighted that their concerns about their son or daughters' emotional difficulties were not listened to by professionals working in intellectual disability services. Mothers appeared to make sense of this in contrasting ways. Sinead felt that professionals had poorer insight into an individual's behaviour than family members:

*"...my friend's emm son he's no longer with us but he emm used to, he was very depressed and emm he he used to lie with his head bent down and his mum said to me, he's like that because he's depressed Sinead but the staff just say oh no he's having a nap, he's sleeping"* (Sinead, 3.457).

In contrast, Breda felt that her son's difficulties were viewed as not serious enough by staff to warrant seeking psychological support, which was influenced by a lack of psychology service provision:

*"I think you really need to be in crisis before you would be referred on to the psychological services at that time"* (Breda, 5.219).

There seemed to be an overarching sense amongst mothers that care staff did not have the same level of commitment to understanding and caring for the needs of their sons and daughters as they did.

*No support available*

Mothers said that help or advice was not forthcoming from health and social care services when they were concerned about their son or daughter's emotional difficulties. Some mothers appeared to feel overwhelmed and isolated in trying to manage their offspring's difficulties, and in the context of additional family commitments or limited social support:

 *"…'coz I had asked my social worker, I had asked I had phoned other people and said there must be other children that have behaviours like Claire out there, how are their families coping, I need some help, I need some advice, and ahh I couldn't get it"* (Sinead, 3.239).

At first sight, mothers' accounts appeared to be confusing; whilst mothers expressed that there was no support available for their son or daughter's emotional difficulties, most did appear to have obtained mental health support from either intellectual disability or generic mental health services for their offspring. The view that no support was available may have reflected the mothers' frustration with the process of accessing services and their perceptions of the available support as unhelpful. Mothers expressed the view that mental health support

often arrived too late. Bernadette felt that funding constraints meant that individuals had to

reach a crisis point, where hospitalisation and sectioning were necessary, before getting the

treatment they required.

Some of the mothers expressed anger and disappointment at the disparity in mental

health and wider health care support available for their offspring compared to individuals

without an intellectual disability. This pervasive disparity in support was apparent despite

carers advocating and voicing their concerns:

*"You feel the feel the health service and everybody has let you down"* (Maureen, 4.483).


In contrast, all mothers valued the support they received from the third sector

organisation PAMIS, with one mother describing this as a "lifeline" (Angela, 1.737). Useful

support included strategies to aid their offspring's emotional difficulties, and peer support for

parents. It is interesting that all mothers particularly valued input from an organisation which

has uncommon specialist knowledge in profound intellectual disabilities.


*Lack of expertise*

Mothers appeared to perceive mental health and intellectual disability services as being

separate, resulting in a lack of knowledge and understanding amongst professionals.

Joanne stated that intellectual disability professionals were at a loss as how to treat her

adopted son's emotional difficulties. Angela, Sinead and Bernadette however, described

mental health professionals as failing to have a sufficient understanding of intellectual

disabilities to appreciate that an individual's behavior may be a means of communicating

their emotional difficulties. There was also a sense that most health and social care

professionals lacked specialist knowledge of severe and profound intellectual disabilities. In

particular, they did not know how to communicate with their sons and daughters. It appeared

that mothers thought it was not solely a lack of expertise that impacted on their offspring's

care, but that many professionals were unwilling to try to understand, and work with their

loved ones:

*"...there's not enough people who understand the conditions (5.100)...I think I think the fact*

*is that a lot of people who work in learning disability do not have the skills for people like*

*our our sons and daughters who have more emm who have deeper needs"* (Breda, 5.107).

One mother, Bernadette, said that she decided not to seek professional help for her daughter

Paula's emotional difficulties, because past input for her older daughter had been unhelpful.

She appeared to have lost confidence in the ability of specialist mental health services to

help:

*"I mean I suppose I didn't seek help because I didn't know what to do I didn't know what*

*anybody could do....because I suppose I felt that there is nobody there to help her you know"*

(Bernadette, 6.527).

*Individuals discriminated against*

Some mothers were angered by their son's and daughter's experience of discrimination by

health and social care professionals, and felt that their offspring were valued less, due to their

level of intellectual disability:

*"I feel as if more so Paula than Mary you're just put in the rubbish bin because well Paula is*

*physically disabled severely, she is nonverbal, she is gastrostomy fed"* (Bernadette, 6.222).

There appeared to be an overarching sense from mothers that professionals

underestimated their offspring's level of understanding and ability, and their potential to

benefit from therapies and specialist support. Some mothers saw this attitude as a barrier to

accessing support. Bernadette described the resistance she had encountered from professionals in getting support for her daughter after transitioning to adult services:

*"I wanted speech therapy for Mary, because Mary's speech her syntax her command of the language is still improving, it gets better every day and I asked for it and got told oh we don't improve once they're adults just maintain, and I said well sorry she is still improving"* (Bernadette, 6.227).

Bernadette's quote captures the real sense of inequality individuals with severe or profound intellectual disabilities face in trying to access services.

**A mother's approach to adapting therapy**

*Taking time to get to know each other*

Given that mothers said professionals did not know how to communicate with their sons and daughters, it is unsurprising that mothers wanted professionals to spend time getting to know their offspring. Bernadette discussed the need for professionals to gain insight into her daughter Mary's distinctive use of basic speech, while other mothers expressed the importance of professionals building rapport in order to detect subtle behavioural indicators signifying changes in mood or engagement:

*"...it's being able to pick up on all the wee signals from their body language from their you know from just looking at their face and saying oh that person looks quite sad today"* (Breda, 5.109).

Mothers often felt that their input was undervalued by professionals. However, mothers thought they could play an important role in helping professionals understand their offspring, and in assisting professionals to be able to communicate with their sons and daughters using idiosyncratic methods. Joanne and Breda described how they had developed

meaningful ways to communicate with their offspring, using touch and clapping of hands, and were able to read a social meaning from their offspring's actions:

"…*So I knew at this time when I was getting this hard clapping that OK you're telling me there's something really bothering you at the moment*" (Joanne, 2.469).

Some of the mothers described how building rapport takes time, with their son or daughter finding meeting new professionals a daunting experience:

"*…you know she's got to build confidence in people you know she's quite fragile that way when it comes to meeting new people she doesn't like it*" (Maureen, 4.444)

Maureen's statement suggests the importance of the relationship between the therapist and client, in facilitating engagement in therapy. A long-standing therapeutic relationship also enables the therapist to build up an experiential understanding of the individual.

## Discussion

This study sought to examine mothers' experiences of accessing mental health support for their son or daughter with severe or profound intellectual disabilities, and mothers' perspectives as to how psychological interventions might be adapted for this population. Although each mother's experience was unique, a number of commonalities were found across participant accounts. Mothers expressed frustration at care staff's tendency to misattribute behavioural indicators of poor emotional wellbeing to their offspring's intellectual disability or physical health problem. However, the mothers acknowledged that even they struggled to recognise signs of emotional difficulties. When mothers did recognise their offspring's distress, it could be difficult to attribute cause, as their loved one could not provide any kind of explanation. These findings appear to be in contrast with Phillip, Lambe & Hogg's (2005) study, in which the majority of carers were able to identify specific behavioural signs that alerted them to their offspring's emotional difficulties.

The findings in this study highlight a number of challenges for individuals with severe or profound intellectual disabilities in getting mental health support. Consistent with a previous report, the mothers stated that they had difficulty getting professionals to take their concerns seriously regarding their offspring's emotional difficulties (The Foundation for people with learning disabilities, 2014). In contrast to Phillip, Lambe & Hogg's (2005) study, where family carers reported that there was no help available for their offspring with emotional difficulties, most mothers in this study appeared to have accessed mental health support for their offspring. Yet this support was not readily accessible, and often only available in times of crisis. Moreover, the support received was not always viewed as helpful, as the mothers did not think that the professionals possessed the specialist knowledge or skills required to work effectively with their sons and daughters. Services did not appear to be

responding to national guidance set out by the National Institute for Health and Care

Excellence (NICE), in terms of professional competencies and training required to deliver

interventions to people with intellectual disabilities and mental health problems (NICE,

2016). However, the mothers thought it was not solely a lack of expertise that impacted on

their offspring's care, but felt that many professionals were unwilling to spend time in trying

to understand and develop the skills to work with their offspring.

Mothers felt that their offspring faced discrimination in accessing interventions for

their emotional difficulties, with some professionals underestimating their potential to benefit

from therapies and specialist support. They also described an age inequality in health care

support, with even less services available for adults in comparison to children. This disparity

extended to every day supports available for individuals, such as day time opportunities in the

community, with mothers describing their offspring's lives as being marked by boredom and

isolation. These findings suggest a lack of progress in services for individuals with more

complex needs, despite longstanding campaigning and policies aimed at redressing the

inequalities these individuals face (The Department of Health, 2009; The Scottish

Government, 2012; 2013).

It was clear that supporting their offspring's emotional difficulties, in the absence of

professional help, had an emotional impact on mothers. Support for the carer should also be

taken into account when planning improved mental health service provision for individuals

with severe and profound intellectual disabilities. A family-centered approach, in which

professionals support both the individual and their carer, has been shown to produce positive

outcomes (Dempsey & Keen, 2008).

Mothers described how psychological interventions might be adapted for their sons

and daughters. They felt that professionals needed to spend time getting to know their

offspring to be able to communicate with them. Indeed, mothers themselves thought they had a potentially important role in therapy, by helping professionals to understand their offspring's idiosyncratic ways of communicating their needs and emotions. Some mothers described using a communication method with their offspring similar to intensive interaction, which is a communication tool for people with complex needs. It involves interpreting non-verbal behaviour and using idiographic communication, such as responsive eye contact and mirroring body or facial expressions. Intensive interaction is thought to have additional benefits for an individual's emotional wellbeing, as it promotes social interaction (Hutchison & Bodicoat, 2015).

There was also a view that therapists would need to take time to build rapport as their offspring can find it difficult to meet and get to know new professionals. Interestingly, the mothers placed emphasis on the therapeutic relationship being important for their offspring with more severe and profound disabilities, just as it has been highlighted as key to therapeutic change by individuals with mild to moderate intellectual disabilities (Pert et. al, 2013).

### *Methodological Strengths and Weaknesses*

A limitation of this study may be the heterogeneity of the included sample. Five of the participants were mothers of sons or daughters with severe or profound intellectual disabilities, with one participant a primary caregiver. However, this participant's perspective was thought to be important as she took on a maternal role, caring for the individual in her home for 5 years. In addition, the mothers had sought professional help for their offspring at different time points, between 1-4 years ago, with one mother seeking help at the time when she was interviewed. This research included a number of questions on Behavioural Activation Therapy as originally a focus of this piece of work was to gain data to assist in the

adaption of this therapy for individuals with severe or profound intellectual disabilities.

However, it was recognized that this set of questions was not in keeping with the IPA

approach to the study of lived experience and these questions were subsequently removed

from the main project analysis. While these questions have been removed, they may have

primed or influenced the results of this study. For example, it may have made mothers more

aware of the lack of psychological therapies accessible to their offspring. However, these

questions were asked at the end of participant interviews and did not seem to influence the

mothers' other responses.

In line with Smith, Flowers & Larkin (2009), a rich transparent and contextualized

analysis of the accounts of participants was provided to enable readers to evaluate

transferability of these findings to other samples. In addition, mothers seemed interested in

sharing their experiences during the interviews, and this may have afforded an uncommon

opportunity for mothers to talk openly in a confidential space about these issues. This study

does not include fathers' experiences, but these are equally important and need to be explored

in future work.

### *Implications for Clinical Practice*

This piece of research has important implications for informing more sensitive and

appropriate mental health service provision for individuals with severe and profound

intellectual disabilities. Emotional difficulties are hard to identify in this population.

Therefore, care staff and family carers could benefit from education and training to help them

detect changes in emotional wellbeing. Health and social care staff do not have the

knowledge or skills required to communicate effectively with individuals with severe or

profound intellectual disabilities. More specialised training is needed for professionals

delivering mental health interventions to individuals, in severe intellectual disabilities and in

non-verbal communication methods, as suggested by the recent NICE guidelines (NICE, 2016). Moreover, having therapies and methods of intervention which are less reliant on speech may be helpful. Behavioural Activation Therapy may offer a suitable option in this regard, given that this therapy relies less on talking, aiming to increase a person's level of meaningful activity to improve mood. Positive results have been found when using this therapy to treat depression in individuals with mild to moderate intellectual disabilities (Jahoda et al., 2017). Individuals also faced discrimination in accessing support for their emotional difficulties. An appropriate pathway of mental health support needs to developed, with a dedicated number of knowledgeable professionals trained to deliver psychological help to individuals with severe and profound intellectual disabilities.

This study offers mothers' perspectives on adapting psychological therapies for individuals with severe or profound intellectual disabilities. Mothers and carers who know an individual best can not only play an important role in helping therapists to understand and communicate with individuals with more severe impairments, but are crucial to supporting the implementation of therapeutic interventions. A long standing therapeutic relationship allows a therapist an experiential understanding of an individual, and helps to build rapport and facilitate engagement.

### *Future research*

Given that this study includes mothers' perspectives of accessing mental health support for their offspring, it would be interesting to extend this research to include fathers' experiences. It may also be useful to explore mental health professionals' perspectives in responding to the mental health needs of services users with severe and profound intellectual disabilities. Further research could aim to trial adapted psychological therapies with this population.

*Conclusion*

This study highlights mothers' commitment to supporting their offspring with emotional difficulties despite facing the considerable challenges they described. Individuals with severe and profound intellectual disabilities and emotional difficulties can have difficulty accessing mental health services, and the support available is often not suited to their needs. More appropriate and sensitive mental health service provision is needed for these individuals. These findings have clinical relevance in informing future research in establishing the effectiveness of psychological therapies for this population.

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# Appendices

*Appendix 1.1*

**SUBMISSION OF MANUSCRIPTS: JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES (JARID)**
Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to http:// mc.manuscriptcentral.com/jarid. If this is the first time you have used the system you will be asked to register by clicking on 'create an account'. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

**Manuscript Files Accepted**

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as **separate** files.
Please upload:
1. Your manuscript without title page under the file designation 'main document'.
2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx files as .doc before uploading.

**Blinded Review**

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

**MANUSCRIPT TYPES ACCEPTED**
*Original Articles, Review Articles, Brief Reports, Book Reviews* and *Letters to the Editor* are accepted. *Theoretical Papers* are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

**MANUSCRIPT FORMAT AND STRUCTURE**

**Format**

**Language:** The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

**Structure**

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

*Cover Page:* A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.
*Running Title:* A short title of not more than fifty characters, including spaces, should be provided.
*Keywords*: Up to six key words to aid indexing should also be provided.

*Main Text:* All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.

*Style:* Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:
-Include all figure legends, and tables with their legends if available.
-Do not use the carriage return (enter) at the end of lines within a paragraph.
-Turn the hyphenation option off.
-In the cover email, specify any special characters used to represent non-keyboard characters.
-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
-Use a tab, not spaces, to separate data points in tables.
-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

**References**

APA - American Psychological Association

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the APA FAQ. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

*Journal article*

Example of reference with 2 to 7 authors

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. The American Journal of Psychiatry, 159, 483–486. doi:10.1176/appi.ajp.159.3.483

Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. *Brain, 126*(4), 841-865. doi: 10.1093/brain/awg076

Example of reference with more than 7 authors

Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., ... Carroll, J. (2004). Sec differences in developmental reading disability: New findings from 4 epidomiological studies. *Journal of the American Medical Association, 291*(16), 2007-2012. doi 10.1001/jama.291.16.2007

*Book Edition*
Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.


**Tables, Figures and Figure Legends**

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.


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for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size. Please submit the data for figures in black and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

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Check your electronic artwork before submitting it: http://authorservices.wiley.com/bauthor/eachecklist.asp.

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*Appendix 1.2*

| **Ebsco psychinfo; last accessed on 180303** | | **Results** |
|---|---|---|
| S1 | TI (profound OR severe) n3 (learning disabilit* OR intellectual disabilit* OR learning difficult* OR developmental disabilit* OR developmental disorder* OR multiple disabilit* OR disabilit*) AB (profound OR severe) n3 (learning disabilit* OR intellectual disabilit* OR learning difficult* OR developmental disabilit* OR developmental disorder* OR multiple disabilit* OR disabilit*) | 6,005 |
| S2 | TI (profound intellectual n2 multiple disabilit*) AB (profound intellectual n2 multiple disabilit*) | 152 |
| S3 | TI (profound n2 multiple learning disabilit*) AB (profound n2 multiple learning disabilit*) | 40 |
| S4 | TI (profound OR severe) n3 (mental retard* OR retard* OR cognitive dysfunct* OR disabled) AB (profound OR severe) n3 (mental retard* OR retard* OR cognitive dysfunct* OR disabled) | 2203 |
| S5 | TI (PMLD OR PIMD OR PMD) AB (PMLD OR PIMD OR PMD) | 690 |
| S6 | DE "Intellectual Development Disorder" OR DE "Multiple Disabilities" OR DE "Developmental Disabilities" | 52,422 |
| S7 | S1 OR S2 OR S3 OR S4 OR S5 OR S6 | 57,487 |
| S8 | TI (happ* OR happ* indic*) OR AB (happ* OR happ* indic*) | 46,459 |
| S9 | DE "Happiness" | 7,821 |
| S10 | S8 OR S9 | 47,941 |
| S11 | S7 AND S10 | 470 |
| **Ebsco Cinahl; last accessed on 180303** | | |
| S1 | TI (profound OR severe) n3 (learning disabilit* OR intellectual disabilit* OR learning difficult* OR developmental disabilit* OR developmental disorder* OR multiple disabilit* OR disabilit*) OR AB (profound OR severe) n3 (learning disabilit* OR intellectual disabilit* OR learning difficult* OR developmental disabilit* OR developmental disorder* OR multiple disabilit* OR disabilit*) | 2,745 |
| S2 | TI (profound intellectual n2 multiple disabilit*) OR AB (profound intellectual n2 multiple disabilit*) | 72 |
| S3 | TI (profound n2 multiple learning disabilit*) OR AB (profound n2 multiple learning disabilit*) | 46 |
| S4 | TI (profound OR severe) n3 (mental retard* OR retard* OR cognitive dysfunct* OR disabled) OR AB (profound OR severe) n3 (mental retard* OR retard* OR cognitive dysfunct* OR disabled) | 281 |
| S5 | TI (PMLD OR PIMD OR PMD) OR AB (PMLD OR PIMD OR PMD) | 203 |
| S6 | (MH "Intellectual Disability") OR (MH "Developmental Disabilities") OR (MH "Disabled") | 36,413 |
| S7 | S1 OR S2 OR S3 OR S4 OR S5 OR S6 | 38,472 |
| S8 | TI (happ* OR happ* indic*) OR AB (happ* OR happ* indic*) | 13,054 |
| S9 | (MH "Happiness") | 1,917 |
| S10 | S8 OR S9 | 13,928 |
| S11 | S7 AND S10 | 291 |
| **Ovid Medline R In process and other non-indexed citations and Ovid Medline R 1946 to present; last accessed on 180303** | | |
| S1 | ((profound OR severe) ADJ3 (learning disabilit* OR intellectual disabilit* OR learning difficult* OR developmental disabilit* OR developmental disorder* OR multiple disabilit* or disabilit*)).ti. OR ((profound OR severe) ADJ3 (learning disabilit* OR intellectual disabilit* OR learning difficult* OR developmental disabilit* OR developmental disorder* OR multiple disabilit* OR disabilit*)).ab. | 7771 |
| S2 | ((profound intellectual) ADJ2 (multiple disabilit*)).ti. OR ((profound intellectual) ADJ2 (multiple disabilit*)).ab. | 70 |

| S3 | ((profound) ADJ2 (multiple learning disabilit*)).ti. OR ((profound) ADJ2 (multiple learning disabilit*)).ab. | 9 |
|---|---|---|
| S4 | ((profound OR severe) ADJ3 (mental retard* OR retard* OR cognitive dysfunct* OR disabled)).ti. OR ((profound OR severe) ADJ3 (mental retard* OR retard* OR cognitive dysfunct* OR disabled)).ab. | 4,617 |
| S5 | (PMLD OR PIMD OR PMD).ti. OR (PMLD OR PIMD OR PMD).ab. | 1,941 |
| S6 | Intellectual Disability/ OR Developmental Disabilities/ OR Disabled Persons/ | 102,921 |
| S7 | S1 OR S2 OR S3 OR S4 OR S5 OR S6 | 113,389 |
| S8 | (happ* OR happ* indic*).ti. OR (happ* OR happ* indic*).ab. | 43,809 |
| S9 | HAPPINESS/ | 3,637 |
| S10 | S8 OR S9 | 45202 |
| S11 | S7 AND S10 | 447 |
| **Ovid Embase 1947 to present; last accessed 180303** | | |
| S1 | ((profound OR severe) ADJ3 (learning disabilit* OR intellectual disabilit* OR learning difficult* OR developmental disabilit* OR developmental disorder* OR multiple disabilit* or disabilit*)).ti. OR ((profound OR severe) ADJ3 (learning disabilit* OR intellectual disabilit* OR learning difficult* OR developmental disabilit* OR developmental disorder* OR multiple disabilit* OR disabilit*)).ab. | 11,838 |
| S2 | ((profound intellectual) ADJ2 (multiple disabilit*)).ti. OR        ((profound intellectual) ADJ2 (multiple disabilit*)).ab. | 103 |
| S3 | ((profound) ADJ2 (multiple learning disabilit*)).ti. OR ((profound) ADJ2 (multiple learning disabilit*)).ab. | 16 |
| S4 | ((profound OR severe) ADJ3 (mental retard* OR retard* OR cognitive dysfunct* OR disabled)).ti. OR ((profound OR severe) ADJ3 (mental retard* OR retard* OR cognitive dysfunct* OR disabled)).ab. | 6,664 |
| S5 | (PMLD OR PIMD OR PMD).ti. OR (PMLD OR PIMD OR PMD).ab. | 2,717 |
| S6 | Intellectual impairment/ OR developmental disorder/ OR disabled person/ | 84,771 |
| S7 | S1 OR S2 OR S3 OR S4 OR S5 OR S6 | 103,239 |
| S8 | (happ* or happ* indic*).ab. or (happ* or happ* indic*).ti. | 65,390 |
| S9 | Happiness/ | 7,648 |
| S10 | S8 OR S9 | 67,655 |
| S11 | S7 AND S10 | 549 |
| **Cochrane Library; last accessed 180303** | | |
| S1 | MeSH descriptor: [Intellectual Disability] explode all trees | 1,235 |
| S2 | MeSH descriptor: [Developmental Disabilities] explode all trees | 566 |
| S3 | MeSH descriptor: [Disabled Persons] explode all trees | 1,190 |
| S4 | S1 OR S2 OR S3 | 2847 |
| S5 | MeSH descriptor: [Happiness] explode all trees | 172 |
| S6 | S4 AND S5 | 2 |
| **Scopus; last accessed 180303** | | |
| S1 | (profound or severe) and ("learning disabilit*" or "intellectual disabilit*" or "learning difficult*" or "developmental disabilit*" or "developmental disorder*" or "multiple disabilit*" or disabilit*) | 37,603 |
| S2 | ("profound intellectual") and ("multiple disabilit*") | 176 |
| S3 | (profound) and ("multiple learning disabilit*") | 65 |
| S4 | (profound or severe) and ("mental retard*" or retard* or "cognitive dysfunct*" or disabled) | 28,207 |
| S5 | (PMLD or PIMD or PMD) | 7,518 |
| S6 | S1 OR S2 OR S3 OR S4 OR S5 | 66,013 |
| S7 | (happ* or "happ* indic*") | 190,603 |
| S8 | S6 AND S7 | 535 |

*Appendix 1.3*

| Quality Rating Protocol | |
|---|---|
| **Authors** | |
| **Title of paper** | |
| **Journal title** | |
| **Date of publication** | |
| **Completed by** | |
| **Completed on** | |

| 1. Design | | |
|---|---|---|
| 1.1 | What is the study design? | 2-Experimental single-case design<br>1-Quasi-experimental design<br>0-Non-experimental design/ Not covered | |
| 1.2 | Is randomisation used? | 1-Yes<br>0-No/ Can't say | |
| **2. Blinding** | | |
| 2.1 | Is blinding used? | 1-Yes<br>0-No/ Can't say | |
| **3. Participants** | | |
| 3.1 | Are inclusion and exclusion criteria, if applicable, and method of recruitment described? | 1-Yes<br>0-No/ Can't say | |
| 3.2 | Is demographic information including, medical, functional and sensory status, and age, sex clearly described? | 1-Yes<br>0-No/ Can't say | |
| 3.3 | Is there any formal assessment to confirm that participants have a severe or profound intellectual disability? | 2-Standardised assessment of IQ (e.g WAIS-IV) or measure of adaptive functioning<br>1-Description of disabilities/ adaptive abilities<br>0-No assessment/ Not covered | |
| **4. Measures** | | |
| 4.1 | Are operational definitions of the target behaviour clearly defined? (indices of happiness) | 1-Yes<br>0-No/ Can't say | |
| 4.2 | How are indices of happiness measured? | 2-Partial interval recording and inter-observer agreement<br>1- Partial interval recording and no inter-observer agreement<br>0- Measure inappropriate to design/population | |
| **5. Intervention** | | |
| 5.1 | Setting and locations where study conducted described? | 2-Yes both covered<br>1-One covered | |

| | | 0-Poorly/ Not covered | |
|---|---|---|---|
| 5.2 | Are baseline and intervention conditions clearly described? | 1-Yes<br>0-No/ Can't say | |
| 5.3 | Was procedural fidelity evaluated? | 1-Yes<br>0-No/ Can't say | |
| **6. Analysis** | | | |
| 6.1 | Were methods used to analyse data appropriate to design? | 1-Yes<br>0-No/ Can't say | |
| 6.2 | Are participants that did not complete, and reasons why described? | 1-Yes<br>0-No/ Not applicable | |
| 6.3 | Are results for each participant reported clearly? | 2- Raw data presented for each measurement point<br>1- Aggregated data presented<br>0-Poorly presented | |
| **Total Score (out of 19)=** | | | |
| **Overall Quality Rating=** | | | |

*Appendix 1.4*

## **Data extraction tool**

**Study name:**

**Aim:**

**Design:**

Study design:

Number of sessions in each experimental phase:

Randomisation:

Blinding:

**Participants:**

Methods of recruitment:

Demographic information:

Assessment of level of learning disability:

**Measures:**

Indices of happiness definition and method of measurement:

Inter-observer agreement:

Favourite stimuli and method of assessment:

**Intervention:**

Intervention used:

Setting and location:

Procedural fidelity:

**Results:**

Raw/ aggregated data:

Main findings:

*Appendix 1.5*

Quality ratings of included studies

| Study | 1.1 | 1.2 | 2.1 | 3.1 | 3.2 | 3.3 | 4.1 | 4.2 | 5.1 | 5.2 | 5.3 | 6.1 | 6.2 | 6.3 | Total | Quality Rating |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Lancioni et al. 2006 | 2 | 0 | 0 | 0 | 1 | 1 | 1 | 2 | 1 | 1 | 0 | 1 | 1 | 1 | 12 | Moderate |
| 2. Lancioni et al. 2007a | 2 | 0 | 0 | 0 | 1 | 1 | 1 | 2 | 0 | 1 | 0 | 1 | 0 | 1 | 10 | Moderate |
| 3. Lancioni et al. 2007b | 2 | 0 | 0 | 1 | 1 | 1 | 1 | 2 | 1 | 1 | 0 | 1 | 0 | 1 | 12 | Moderate |
| 4. Lancioni et al. 2007c | 2 | 0 | 0 | 1 | 1 | 1 | 1 | 2 | 0 | 0 | 0 | 1 | 0 | 1 | 10 | Moderate |
| 5. Lancioni et al. 2011 | 2 | 0 | 0 | 1 | 1 | 1 | 1 | 2 | 1 | 1 | 0 | 1 | 0 | 1 | 12 | Moderate |
| 6. Lancioni et al. 2012 | 2 | 0 | 0 | 1 | 1 | 2 | 1 | 2 | 1 | 1 | 0 | 1 | 0 | 1 | 13 | Moderate |
| 7. Lancioni et al. 2013a | 2 | 0 | 0 | 0 | 1 | 1 | 0 | 2 | 0 | 0 | 0 | 1 | 0 | 0 | 7 | Poor |
| 8. Lancioni et al. 2013b | 2 | 0 | 0 | 0 | 1 | 1 | 1 | 2 | 0 | 1 | 0 | 1 | 0 | 1 | 10 | Moderate |
| 9. Lancioni et al. 2013c | 2 | 0 | 0 | 1 | 1 | 1 | 1 | 2 | 0 | 1 | 0 | 1 | 0 | 1 | 11 | Moderate |
| 10. Stasolla and Caffo 2013 | 2 | 0 | 0 | 1 | 1 | 1 | 1 | 2 | 1 | 1 | 0 | 1 | 0 | 1 | 12 | Moderate |
| 11. Lancioni et al. 2014 | 2 | 0 | 0 | 0 | 1 | 1 | 1 | 2 | 0 | 1 | 0 | 1 | 0 | 1 | 10 | Moderate |
| 12. Darling and Circo 2015 | 2 | 0 | 0 | 1 | 1 | 1 | 1 | 2 | 1 | 1 | 1 | 1 | 1 | 1 | 14 | Moderate |
| 13. Stasolla et al. 2018 | 2 | 0 | 1 | 1 | 1 | 2 | 1 | 2 | 1 | 1 | 0 | 1 | 0 | 2 | 15 | Good |

*Appendix 2.1*

**SUBMISSION OF MANUSCRIPTS: JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES (JARID)**

Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to http:// mc.manuscriptcentral.com/jarid. If this is the first time you have used the system you will be asked to register by clicking on 'create an account'. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

**Manuscript Files Accepted**

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as **separate** files.
Please upload:
1. Your manuscript without title page under the file designation 'main document'.
2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx files as .doc before uploading.

**Blinded Review**

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

**MANUSCRIPT TYPES ACCEPTED**

*Original Articles, Review Articles, Brief Reports, Book Reviews* and *Letters to the Editor* are accepted. *Theoretical Papers* are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

**MANUSCRIPT FORMAT AND STRUCTURE**

**Format**

**Language:** The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

**Structure**

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

*Cover Page:* A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.
*Running Title:* A short title of not more than fifty characters, including spaces, should be provided.
*Keywords*: Up to six key words to aid indexing should also be provided.

*Main Text:* All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.

*Style:* Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:
-Include all figure legends, and tables with their legends if available.
-Do not use the carriage return (enter) at the end of lines within a paragraph.
-Turn the hyphenation option off.
-In the cover email, specify any special characters used to represent non-keyboard characters.
-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
-Use a tab, not spaces, to separate data points in tables.
-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

**References**

APA - American Psychological Association

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the APA FAQ. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

*Journal article*

Example of reference with 2 to 7 authors

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. The American Journal of Psychiatry, 159, 483–486. doi:10.1176/appi.ajp.159.3.483

Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. *Brain, 126*(4), 841-865. doi: 10.1093/brain/awg076

Example of reference with more than 7 authors

Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., ... Carroll, J. (2004). Sec differences in developmental reading disability: New findings from 4 epidomiological studies. *Journal of the American Medical Association, 291*(16), 2007-2012. doi 10.1001/jama.291.16.2007

*Book Edition*
Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.


**Tables, Figures and Figure Legends**

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.


**Preparation of Electronic Figures for Publication**
Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable

for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size. Please submit the data for figures in black and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

Further information can be obtained at Wiley-Blackwell's guidelines for figures: http://authorservices.wiley.com/bauthor/illustration.asp.

Check your electronic artwork before submitting it: http://authorservices.wiley.com/bauthor/eachecklist.asp.


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*Appendix 2.2*

**Interview Topic Guide**

Interview preparation

> ➢ Remind participant that participation in the study is voluntary
> ➢ Remind participant about the parameters of confidentiality
> ➢ Remind participant that they can stop the interview or they can take a break at any time

Introduction

Thank you for agreeing to talk to me today. My name is Tracey. For this research study, I am interested in hearing a bit about ___ (name of individual with severe or profound LD), and your experience seeking support for their emotional difficulties. I am also interested in finding out your expert opinion and views about how a psychological treatment, such as behavioural activation, might be adapted for someone with a severe or profound intellectual disability. Feel free to ask any questions at any time if there is anything I say that is not clear, and there will be an opportunity at the end for you to ask any further questions you may have.

*Ask participant to sign consent form before proceeding. Begin recording *

Context

- Can you tell me a bit about ___ (name of individual)? What is he/she like?
- Can you tell me a bit about his/her life? How does he spend his /her time?
- Is he/ she involved with any services? Attend a day service?
- Can you describe to me your family situation?

Experience getting Support

- Was there a time when you thought (name of individual) had an emotional difficulty?
- How did you realise (name of individual) had an emotional difficulty?
- Were there any factors that might have contributed to (name of individual) developing emotional difficulties?
- Can you tell me about your experience of getting support for (name of individual) emotional difficulties?
- Who did you get support from? What services? Why did you approach these services?
- How did you access this support? How did you find out about it?
- What did this support entail/ look like?
- Were there any barriers/ difficulties in getting support?
- Did you get support from any mental health service? Or mental health professional?
- Were you aware of any specialist mental health support available?

Treatment of emotional difficulties

- What was helpful in improving his/her emotional difficulties? Were there any strategies or approaches in particular?
- What support was unhelpful or didn't work so well? Were there any strategies or approaches in particular?

Adapting psychological treatment

- What is your impression of behavioural activation?
  Prompts: How do you feel about it? What kind of thoughts do you have about it?
- How would behavioural activation be best adapted to make it suitable for someone with a severe or profound intellectual disability?
- Can you see any challenges or barriers to using it with people with severe or profound intellectual disability?

Ending

- Is there anything you would like to say that we didn't touch on so far?
- Do you have any questions?

*Appendix 2.3*

# University of Glasgow | College of Medical, Veterinary & Life Sciences

## Listening to families: making psychological interventions more accessible for people with severe or profound and multiple learning disabilities

## Information for participants in the research project

1.       **Study title**

Listening to families: making psychological interventions more accessible for people with severe or profound and multiple learning disabilities.

2.       **Invitation**

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with friends or relatives if that would be helpful for you. We are also very happy to answer any questions that you might have or give you more information that you might want. Our contact details are at the end of this document. Please take time to decide whether or not you wish to take part.

3.   **What is the purpose of the study?**

There is research to suggest that people with severe or profound and multiple learning disabilities (PMLD) are more likely to experience mental health problems during their lives, than people without a learning disability. However, there can be difficulties for individuals with severe or profound learning disabilities accessing mental health services, and little is known about effective psychological treatment for these individuals. Mothers play a very significant role in supporting their loved one with a severe or profound learning disability, yet there has been little research about mothers' views.

In this study we want to find out about mothers' experiences and views. It is hoped that the insight into mothers' views will help with the provision of mental health support for people with severe or profound learning disabilities, and help professionals to adapt psychological treatment for these individuals.

4.       **Why have I been chosen?**

You have been asked to take part in the study because an organisation in contact with you thinks that you are a mother of an adult with a severe or profound and multiple learning disability in the right age range for the study (over 18 years), and have experience seeking

support for their emotional difficulties. We are hoping to recruit around 6 to 10 participants for this study.

**5.      Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep, and you will be asked to sign a consent form.  You will be given a copy of your consent form to keep.  If you do decide to take part you are still free to withdraw at any time without giving a reason.  Deciding not to take part will not impact any other aspect of your relationship with University of Glasgow or the voluntary organisation that you receive a service from.

**6.      What will happen to me if I take part?**

The researcher, Tracey Adams, will arrange to meet with you in the premises of the voluntary organisation you receive a service from, at a convenient time for you. There will also be an option for you to take part in the study via telephone. We will ask everyone to complete an interview, this could take from 60 – 90 minutes. The questions will include a description of your family, your experience of seeking help for your loved ones emotional difficulties, helpful and unhelpful strategies in the treatment of these difficulties, and your views about ways of making psychological treatments more accessible for people with severe or profound and multiple learning disabilities. You can stop the interview at any time, to take a break or if you decide you no longer want to take part.

**7.      What do I have to do?**

If you decide you want to take part in the study or you want to ask for further information, please contact the researcher using the contact details at the end of this information sheet. You can also supply your name and contact details on the opt-in form at the bottom of this information sheet, and send this to the researcher in the post (stamped addressed envelope provided), or by giving this opt-in form to the person that told you about the study.

If you are happy to be contacted in relation to this study, please tell the person that told you about the study.  A member of administration team will then contact you within two weeks to check that you have all the information that you need. They will only contact you if you give permission to do so.

If you decide you do wish to take part, the researcher, Tracey Adams, will meet with you to ask you questions with regard to your loved one's emotional difficulties, which should last around 60 – 90 minutes.  Although there will be a general structure to the interview, the information you give will guide the interview.  You will be able to raise any other issues you want to discuss at the end of the interview.  You will be able to take a break or stop the interview at any time.

8.     **What are the possible disadvantages and risks of taking part?**

We do not anticipate that there will be any risk to you completing the interviews. However, we do recognise that this may be an emotive topic for you and if you do become distressed during the interview, you will be offered a break or to stop the interview at any time.

9.     **What are the possible benefits of taking part?**

Whilst there will be no direct benefits to you, the study will improve our understanding of mothers' experiences and views. We will use the results from this study, to help inform more sensitive and appropriate support for people with severe and profound and multiple learning disabilities, and to help adapt psychological treatment for these individuals.

10.    **Will my taking part in this study be kept confidential?**

All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it.  We might use direct quotations from your interview in the final report, however, you will not be able to be identified by this information and you will need to provide consent in order for us to do this.

Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

11.    **What will happen to the results of the research study?**

We hope to publish this article in a scientific journal.  If this is the case, you will not be identified in this publication.

If you would like, we will send you an information sheet providing you with an outline of the results of this study. We hope that the results will provide a greater understanding of mothers' points of view. In turn, we hope that this understanding will help to provide more sensitive support to people with severe and profound learning disabilities and mental health problems. We also hope that it will help professionals adapt psychological treatment to make it more accessible to for these individuals.

12.    **Who is organising and funding the research?**

There is no specific funding for this research which is being organised by the University of Glasgow.

13. **Who has reviewed the study?**

This project has been reviewed by the College of Medical, Veterinary and Life Sciences, University of Glasgow Ethics Committee.

14. **Contact for Further Information**

If you have any further questions please contact Tracey Adams, Trainee Clinical Psychologist

By telephone: 01463 705597
Or email: t.adams.1@research.gla.ac.uk

**Thank you for taking the time to read through this information sheet.**

………………………………………………………………………………………………………………………………………

# Listening to families: making psychological interventions more accessible for people with severe or profound and multiple learning disabilities

## Opt-In Form

**I am happy for Tracey Adams, Trainee Clinical Psychologist, to contact me on the following phone number(s) to discuss taking part in the above study.**

**Name:**
……………………………………………………………….

**Home telephone number:**
……………………………………………………………….

**Mobile telephone number:**
……………………………………………………………….

*Appendix 2.4*

**University of Glasgow | College of Medical, Veterinary & Life Sciences**

**Behavioural Activation Information Sheet**

**Background**

People with severe or profound and multiple learning disability (PMLD) may be at an increased risk of developing mental health problems, and very little is known about effective psychological therapy for these individuals. A psychological therapy called 'Behavioural Activation' may be suitable for people with a more severe or profound learning disability, given that this treatment relies less on talking and having to tell someone about their difficulties.

**What is Behavioural Activation (BA)?**

BA is a psychological therapy to help people who are feeling depressed or low in mood. This is a tried and tested treatment, and has recently been used with people with mild to moderate learning disabilities with positive results. It aims to increase important and enjoyable activities in a person's life, that help bring a sense of pleasure and accomplishment, which results in an improvement in mood.

When people feel depressed or low, they often stop doing activities or engaging in things they used to enjoy. This means that they have less pleasure in their lives and little to look forward to on a day to day basis, which can keep them feeling low. This treatment involves people re-establishing or trying out new daily routines, or activities they may enjoy or find engaging, to help people feel better and improve mood. It helps people break their day into different parts, including social, home or day time activity.

**What's involved?**

Introduction: The therapist spends time getting to know the client and their supporter, building rapport and engaging them in the work.

Activity diaries: The supporter that knows the client well, helps the client to monitor their daily level of activity and mood between treatment sessions using an activity diary. Activity diaries are useful in gathering information about how the client is spending their time, and to what extent these activities are making the client feel better or worse.

Patterns of activity and like and dislikes: The therapist uses a variety of methods to find out from supporter or client about the clients present and past activities, and new activities they might like to try. A great deal of time is spent finding out about activities that the client likes and things that are important to them in their life.

Activity scheduling: The supporter, with the help of the therapist choose activities that the client may like to do more of, that give them a sense of pleasure and achievement. A planning sheet is used to plan client's activities in between treatment sessions. It is used to consider when and where an activity is to be scheduled, how often it is to be completed, and who the activity is to be carried

out with. This is a personal and flexible document which will change as activities are tried out, involving trial and error to find out what works best.

Overcoming barriers to change: Possible barriers which may hinder the client's progress are considered, such as the client becoming anxious or upset in certain places, or more practical concerns such as the need for transport or extra help for supporter.

**Taking part in the research study**

We would be interested in hearing your views on Behavioural Activation (BA), and how best to adapt it, or make it relevant and meaningful to your son or daughter, in a way that we would be able to help.

*Appendix 2.5*

| Sample of IPA analysis- First and Second Level Coding | | |
|---|---|---|
| **Emergent Themes** | **Original Transcript** | **Initial Noting** |
| Searching for advice/ support<br><br>Past self as unknowledgeable (process)<br><br>Daughter's behaviour as unmanageable<br><br>Professional not competent<br><br>Lost confidence in support<br><br>Help in form of CBF<br><br>Progress in support available with time<br><br>PAMIS as a link to helpful support | **I: And just on the mental health side of things, so you said there's a long waiting list, would you have known who to contact if you did want to?**<br><br>P: Yeah yes I would probably have went through the learning disability nurse, I mean I had gone through the mental health emm when Claire was younger, emm at (name of service) emm and we had now we had seen the psychologist there, and it was really <u>strange</u> because this is when I was <u>trying</u> to find out why Claire was behaving the way she was, I hadn't the knowledge that I had now, and didn't understand that behaviour has a function, and I had gone along to see her and I had Claire had been very violent, head banging us all and she was going upstairs and she was (inaudible- a big girl?) and we couldn't get her back down again and emm the the psychologist said to me emm well when she is coming back down the stairs you say to her that this you know this behaviour is not acceptable and when she said that I thought <u>oh I don't think she is understanding</u> because when your child gets to such a situation of anxiety, language means nothing to them you know they've lost that ability to process the language, when she's headbutting and punching me, you don't give her no language, because she can't comprehend language, so I didn't feel confident (laugh) in the system when the lady said this to me, and emm I went back and forward, it was quite, I had 2 other children, and emm I I felt that it was a waste of time to be quite honest with you so I I didn't keep up going back, emm at that stage the the challenging behaviour foundation at that stage were <u>much</u> more helpful to me. So that's how that's how it progressed, but that's a few years ago remember, things have changed for the better.<br><br>**I: Aha, and the challenging behaviour foundation how did you hear about that?**<br>P: That was through PAMIS, emm I found that out through PAMIS, emm they had just received emm a video emm as a resource for | Emphasis on 'Strange'- unexperienced/ poor/ bad practice?<br>Emphasis on 'Trying'. Trying to find out why Claire behaving in a certain way, didn't understand, wanted support/ advice<br>More knowledgeable than back then - process of gaining more knowledge<br><br><br><br>Claire violent towards family, difficult situation, family in crisis?<br><br><br><br>Change in tone 'oh'- considering this as unhelpful? Lost confidence, psychologist 'not getting it'. How are you going to help me? Professional not understanding<br><br><br>Not feeling confident in system. Laugh – feeling advice or her experience with psychologist a bit of a joke/ now worthy of respect? Awkward discussing this?<br>Backwards and forwards- seesaw metaphor- feeling desperate? Hopeless? Was this a difficult time for mum in context of caring for her other young children? Mum not being helped/ supported.<br><br><br>Emphasis on 'much'- contrast- specialist knowledge<br>Difference between help received then and now.<br><br><br><br>PAMIS linking her to helpful information. Was this new information to PAMIS too? PAMIS not |

| | the organisation, 'coz I had asked my social worker, I had asked I had phoned other people and said there must be other children that have behaviours like Claire out there , how are their families coping, I need some help, I need some advice, and ahh I couldn't get it, and emm the lady ehh Vivienne Coooper who started up the challenging behaviour foundation she has a son with a rare syndrome she found herself in the same situation as me and she started the organisation maybe 20 years ago, for that very reason, because there was information out there but it wasn't in the one place and now she runs the organisation, and helps families, and does talks all over the world emm on challenging behaviour so emm they were much more helpful to me, because they sent videos and free resources and when you see a child on a video doing exactly, and when you hear a parent talking exactly like you, you think oh I'm not alone here (laughs). <u>This poor lady is in my shoes aswell</u>! (raised tone) emm and they're a great support network, theyre a great support network as well, so that's that's what helped. But emm (pause) and also emm I think now I don't know if it's happening all over, but mental health and emm learning disability are kind of joining up together. I don't know if you've heard about that? | knowing either? Where do mothers turn? |
|---|---|---|
| Searching for support/ advice | | Asking multiple professionals for help/ advice Feeling alone/ no support Family not coping Feeling helpless? |
| Self as helpless/ family not coping | | |
| Other mothers as helpless | | |
| Transformation to helper (other mothers) | | Founder of CBF also in same situation, also no help. Normalising for mother. Helpless to role of helper Now helps families, set up CBF. Information, resources how to manage persons behaviour. |
| | | Normalising positive effect for Sinead, gained support, less isolated |
| Normalising of her situation | | Emphasising feeling of being totally alone. Laugh- Emotive/ uncomfortable for mother? |
| Mother as supported | | |

*Appendix 2.6*

As previously mentioned, the mothers' more general views about adapting psychological therapies for their offspring were included in the results section of this study. The data from participant interviews specifically relating to behavioural activation therapy will be reported in another paper. This data refers to specific adaptations and barriers in using this approach with individuals with severe or profound intellectual disabilities. A general overview of the themes generated during analysis relating to behavioural activation is given below:

Table 1. Superordinate and subordinate themes

| | |
|---|---|
| Adapting psychological therapy | Alternate forms of communication |
| | Monitoring activation |
| | |
| | Limited means of communication |
| Barriers to intervention | Lack of accessible activities |
| | Implementation and relying on others |

*Appendix 2.7*

# University of Glasgow | College of Medical, Veterinary & Life Sciences

Project Number:
Subject Identification Number:

## CONSENT FORM

**Title of Project:** Listening to families: making psychological interventions more accessible for people with severe or profound and multiple learning disabilities

**Name of Researcher(s):**
Tracey Adams
Professor Andrew Jahoda

Please initial box

I confirm that I have read and understand the information sheet dated 24.11.2017 (version 4) for the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

☐

I agree for the interview to be tape-recorded.

☐

I agree for anything I say to be used in the final report about this research. I understand that I will not be able to be identified from the information that is published.

☐

I agree to take part in the above study.

☐

_____        _____        _____
*Name of subject*                          *Date*                    *Signature*

_____        _____        _____
*Name of Person taking consent*     *Date*                    *Signature*
(if different from researcher)

_____        _____        _____

*Researcher*                       *Date*                *Signature*

*Appendix 2.8*

![University of Glasgow | College of Medical, Veterinary & Life Sciences]

Dr. Dorothy McKeegan

College Ethics Officer

Room 303, Institute of Biodiversity Animal Health and Comparative Medicine

Jarett Building

Glasgow, G6 11QH

23rd August 2017

Dear Professor Jahoda

**MVLS College Ethics Committee**

***Project Title:***    Listening to families: making psychological interventions more accessible for people with profound and multiple learning disabilities
***Project No:***  200160168

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Project end date: 30 June 2018
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research:
  ([http://www.gla.ac.uk/media/media_227599_en.pdf](http://www.gla.ac.uk/media/media_227599_en.pdf))
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

*Dorothy McKeegan*

*Appendix 2.9*

**DOCTORATE IN CLINICAL PSYCHOLOGY**


# SUBMISSION FRONT PAGE


**Matriculation Number: 2230377A**


**Name of Assessment: MRP Proposal**


**Title of Project: Mental Health and Profound and Multiple Learning Disability.**


**Academic Supervisor: Dr. Andrew Jahoda**


**Field Supervisor: N/A**

*(If Applicable)*


**Submission Date to Supervisor: 30th January 2017**


**Version Number: 3**

**Word Count: 3,113**

**Abstract**

**Background:** Previous research has shown that individuals with Profound and Multiple Learning Disabilities (PMLD) may be more susceptible to mental health problems than the general population and individuals with milder learning disability. There is also evidence to suggest that individuals with PMLD may have difficulties accessing mental health services, and little is known currently about effective psychological interventions for individuals with PMLD. Previous research has not considered carers perspectives in relation to this.

**Aims:** (i) To explore carers' experience of seeking support for their loved one with PMLD's emotional difficulties; (ii) carers' experiences of working alongside professionals to establish helpful and unhelpful strategies in the treatment of their offspring's mental health problems; and (iii) carers' views about ways of making psychological treatments, in particular behavioural activation more accessible for people with PMLD.

**Plan of Investigation:** This study will use a qualitative design. A semi-structured interview will be conducted with carers of people with PMLD. It is hoped that 6-10 carers will be recruited from PAMIS, a voluntary organisation that supports people with profound and complex needs and their families. This study will use Interpretative phenomenological analysis to analyse participant's interview transcripts.

**Practical applications:** This research may help to inform more sensitive and appropriate service provision and the adaptation of psychological therapies for individuals with PMLD.

**1.0 Introduction**

**1.1 Profound and Multiple Learning Disabilities (PMLD)**

There is much variation in the definition of Profound and Multiple Learning Disabilities (PMLD), despite its widespread usage as a term. People with PMLD, despite their age and experience, are at an early stage of intellectual, communicative, social and emotional development and usually need support for most activities. In addition, individuals with PMLD are likely to have sensory or physical problems (Sheehy & Nind, 2005). The World Health Organisation (2004) defines profound intellectual disability as having an IQ under 20, resulting in severe limitation in self-care, continence, communication and mobility.

**1.2 Profound and Multiple Learning Disabilities (PMLD) and mental health**

There is an awareness of the high incidence of mental health difficulties in the general population, with 1 in 4 individuals thought to experience a mental health problem each year in the UK (The Health & Social Care Information Centre, 2009). However, it is also known that people with learning disabilities are more likely to experience mental health difficulties during their lives than the general population (Cooper & van der Speek, 2009), with some research indicating mental health difficulties can increase in proportion to the severity of the disability (Sheehy & Nind, 2005). Furthermore, individuals with more severe cognitive impairment are likely to engage in fewer purposeful activities (Jones et al., 1999) and experience a poorer quality of life (Perry & Felce, 2003).  Therefore, it is reasonable to assume that individuals with PMLD may be more sensitive to mental health challenges than the general population and other individuals with milder learning disabilities. However, it is only a relatively recent idea that individuals with severe cognitive impairment have the capacity to experience stress and emotion, and research in the area of mental health and PMLD is needed.


**1.3 Barriers to accessing treatment for mental health difficulties**

Individuals with PMLD seeking treatment for mental health difficulties face a number of obstacles. Firstly, mental health problems are often not recognised in individuals with PMLD. For example, individuals with PMLD may have limited receptive and expressive language abilities, and consequently may not be able to describe their distress and seek help. This means that someone else has to recognise that an individual is showing signs of mental health problems. Thus, carers have an important role in recognising possible signs of emotional distress, for example changes in appetite, sleeping pattern, becoming withdrawn, and self-injurious behaviour (PAMIS, 2011).

As individuals with PMLD can express their feelings using behaviour, it can be difficult to distinguish challenging behaviour from mental ill-health, or to see the link between challenging behaviour and poor mental health (PAMIS, 2011). In addition, diagnostic overshadowing may occur, where presenting problems are ascribed to an individual's learning disability rather than treatable mental health problems (Carr et al, 2016).

It has also been recognised that there are inequalities in the way people with profound learning disabilities are supported by health and social care services (Department of Health, 2010). Valuing People Now (Department of Health, 2009) highlighted that commissioners and policy makers were not sufficiently addressing the needs of people who had more complex needs. In addition, Raising Our Sights (Mansell, 2010) reported challenges facing individuals with PMLD, including experiencing discrimination in accessing services and encountering low expectations from staff of what is possible to achieve for people with PMLD. Some research has suggested that people with learning disabilities and their carers have difficulty in accessing mental health services specifically. Carers reported that getting GPs to believe their concerns or getting them to refer individuals for specialist help were the main barrier to accessing support for their son or daughter's mental health problem (Burke, 2014).

### 1.4 Treatment for mental health difficulties

Medication is commonly prescribed to treat mental health problems in individuals with learning disabilities (Carr, 2016). It is estimated that around 50 percent of adults with learning disabilities are prescribed psychotropic drugs, with 20-25 percent using antipsychotics and 12% using antidepressants (NICE, 2016). The next most commonly used interventions are psychosocial interventions. However, there are few evidence based psychological therapies treatment for mental health problems in individuals with intellectual disabilities, and very little is known about psychological therapy for individuals with more complex needs, including people with PMLD (The British Psychological Society, 2016; Matrix, 2015).

Over the past few years, there has been a focus on adapting cognitive behavioural therapy (CBT) for individuals with learning disabilities, and this has had promising results (Vereenhooghe & Langdon, 2013). However, findings suggest that talking therapies like CBT may not be accessible for individuals with more significant impairments because of excessive cognitive and communicative demands. Recently, the effectiveness of behavioural activation for individuals with learning disabilities and depression has been evaluated (Jahoda et al., 2015). Behavioural activation aims to increase a person's level of meaningful activity and access to positive reinforcers, and has proven to be as effective as cognitive behavioural therapy in the general population (Ekers et al., 2008). Given that this therapy relies less on communicative demands, it may be useful for individuals with learning

disabilities, and in particular for those with more profound and multiple disabilities. However, given the lack of knowledge about psychological therapy for people with PMLD, more research needs to be conducted as to how a therapy like behavioural activation could be adapted for this population. Research has not yet engaged with carers of people with PMLD to obtain their perspectives on this issue.

**2.0 Aims and rationale for proposed study**

Previous research has suggested that individuals with PMLD may be at an increased risk of developing mental health problems. In addition, people with PMLD may have difficulties accessing mental health services, and very little is known currently about effective psychological interventions for individuals with PMLD. The proposed study aims to address this gap and use Interpretative phenomenological analysis (IPA) to generate rich and detailed accounts of (i) carer experiences of seeking support for their loved one with a profound and multiple learning disability's emotional difficulties; (ii) experiences of working alongside professionals to establish helpful and unhelpful strategies in the treatment of their offspring's mental health problems; and (iii) carer views about ways of making psychological treatments, in particular behavioural activation more accessible for people with PMLD. IPA lends itself particularly well to this task given its inductive approach, capacity to describe and analyse lived experience, and ability to capture the meaning and common features, of an experience or event (Starks & Trinidad, 2007).

**3.0 Plan of Investigation**

**3.1 Participants**

It is hoped that carers of adults with PMLD will be recruited from PAMIS, a voluntary organisation that provides support for people with PMLD, their family and carers. There is a PAMIS branch based in Inverness, and branches in Glasgow and Dundee. Between 6-10 participants will be recruited for this study. Socio-demographic information will be recorded for all carers and adults with PMLD, including gender, age, post-code. Medical and psychiatric diagnoses of individual with PMLD will also be collected, and marital status, occupation and relationship of carer to individual with PMLD.

**3.2 Inclusion Criteria**

1. Carer must look after an individual over the age of 18 with a diagnosis of a profound and multiple learning disability (PMLD).

2. Must have experience seeking support for behavioural or emotional difficulties of the individual with PMLD they are caring for.

3. Involved with PAMIS voluntary organisation.

4. English must be first language.

5. Written consent must be obtained from carer.

**3.3 Recruitment procedure**

Prior to recruitment, the researcher will provide information to relevant PAMIS staff about the study, its eligibility criteria and procedures for recruitment. PAMIS staff members will be invited to identify carers that meet the eligibility criteria. The researcher will go along and speak at a PAMIS group meeting to relevant families to provide information about the study. The researcher will prepare a participant information sheet, which will include the researchers email address and telephone number, and a section detailing an opt-in form. Participants will be given the option to contact the researcher directly via phone/email to show interest in taking part in the study, or by supplying their name and contact details on the opt-in form, giving permission for the researcher to contact them. Interested potential participants will be invited to send the opt-in form via post to the researcher (stamped addressed envelopes will be provided) or by giving the opt-in form to a PAMIS staff member to be passed onto the researcher to follow up.

An additional recruitment procedure may also be used, involving PAMIS staff members sending information about the study by post, to families that meet the study eligibility criteria. Potential participants will receive a participant information sheet with opt-in form as detailed above and a stamped addressed envelope to the researcher. Interested participants will be contacted directly by telephone by the researcher to arrange an appointment for interview at their convenience. The opportunity to ask further questions will be available to participants before being asked to provide informed consent to take part in the study.

**3.4 Interview**

A semi-structured interview will be conducted on an individual basis and are expected to last approximately 1 -1.5 hours, and will be recorded using a digital voice recorder. The researcher, along with the study supervisor and PAMIS staff, will develop an interview schedule containing between 6 and 10 questions, informed by the topics discussed above. It will also contain possible prompts to use during the interview process. As Interpretative Phenomenological Analysis (IPA) is used to gain an insight into a person's everyday lived experience of events there will be scope for interviews to venture away from the interview schedule if this will result in richer interview content. IPA is an iterative process, the interview will be piloted with a small number of participants to practice interview technique and to make sure appropriate topic areas are being covered.

**3.5 Design**

The study will use a retrospective qualitative design, and data will be analysed using IPA. This involves carrying out one to one interviews with participants, transcribing those interviews and then exploring the content of the interviews to identify recurring themes. This method of qualitative analysis will be used, as IPA focuses on peoples lived experiences, understandings and viewpoints of particular phenomena. This method will appropriately address the research questions relating to carers' experience of seeking support for their offspring with PMLD's emotional difficulties, their experience of helpful and unhelpful treatment strategies, and views about ways of making psychological treatments, in particular behavioural activation more accessible for people with PMLD.

**3.6 Research procedures**

Interviews will be conducted by the researcher within PAMIS offices or public buildings used by PAMIS. At the beginning of each participant interview, a brief outline of the research project will be given and an outline of the nature of the interview, making the participant aware that the researcher recognises and is seeking their expert knowledge of their family member with PMLD. The research study information sheet will be read through again with each participant. Participants will be reminded that their participation is voluntary and confidential and that they are free to withdraw at any time. The confidentiality policy will be explained to each participant, and that patient identifying information will be removed, and information will be recorded using a pseudonym during the interview and analysis.  Participants will be made aware that the interview will be audio recorded, with the permission of the participants. Participants will be offered an opportunity to ask any further questions, and if they are happy to be involved written consent will be obtained. After the interview is completed, it will be transcribed by the researcher who will anonymise references to persons and places. The transcripts will be checked for completeness and accuracy by comparing with the source recording. Once all interviews have been transcribed and checked, data analysis will commence.

**3.7 Data analysis**

Interpretive Phenomenological Analysis (IPA) will be used to analyse this data. Analysis will follow 6 steps, as set out by Smith, Flowers and Larkin (2013). These steps are; (i) Reading and re-reading (ii) Initial noting (iii) Developing emergent themes (iv) Searching for connections across emergent themes (v) Moving to the next case (vi) Looking for patterns across cases.

**3.8 Justification of sample size**

IPA research is typically based on small sample sizes of 4-10 participants, with each person interviewed once. This is the number of participants that Smith et al. (2012) recommend for a

doctorate level research project. This study will seek a sample size of 6-10 participants (including pilot interviews), depending on respondent rates and the richness of the data collected.

**3.9 Settings and Equipment**

Participant recruitment will require participant information sheets, consent forms and stamped addressed envelopes. Interviews will be conducted by the researcher within PAMIS offices or public buildings used by PAMIS. The interviews will be one- to-one, and will be audio-taped using a voice recorder. Recordings and transcripts will be stored on an NHS computer desktop.

**4.0 Health and Safety Issues**

**4.1 Researcher Safety Issues**

All interviews will take place within normal working hours in PAMIS offices or public buildings used by PAMIS, and will comply with standard safety procedures. When participants are being interviewed, PAMIS staff will be aware of this and will be available if required.

**4.2 Participant Safety Issues**

Written consent will be obtained from participant and information made available on the opportunity to opt-out. Confidentiality will be explained to participants at the outset of the study and participant will have an opportunity to ask any questions. The researcher will remind the participant that they can take a break or stop the interview and remove consent to the study at any time without needing to provide a reason. The researcher will do frequent 'check-ins' with participant to check for fatigue or distress and ensure they are happy to continue.  If carer discloses information related to risk to self or others, researcher will act appropriately, respecting limits of confidentiality. If psychological difficulties become apparent, this will be discussed with carer and they will have option of asking for a referral to be made to adult mental health psychology services.

**5.0 Ethical Issues**

Information obtained during participant interviews will be confidential and will be stored in a locked filing cabinet, with only the researcher having access to the filing cabinet. Ethical approval will be sought from Glasgow University Ethics Committee.

**6.0 Financial Issues**

Equipment costs will include one digital voice recorder and transcribing kit (to be borrowed from the University of Glasgow). Funding will be required for printing 30 participant information sheets and

and 10 consent forms, and 20 stamped addressed envelopes and labels for interested potential participants.

**8.0 Timetable**

**May 2017**- Submit final approved proposal

**August 2017**- Apply for ethical approval

**October 2017**- Commence recruitment and data collection

**January 2018**- Data analysis

**March 2018**- Draft MRP to supervisor

**May-June 2018**-  Submit research to university

**September 2018**- Viva

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*Proposal Appendix 1*

**Plain English Summary**

**Title:** Mental Health and Profound and Multiple Learning Disability.

**Background:** An individual with a profound and multiple learning disability (PMLD), has a severe learning disability, with limited ability to communicate and additional physical and sensory problems, such as eyesight or hearing loss. There is some research to suggest that people with PMLD are more likely to experience mental health problems during their lives, than people without a learning disability and people with a milder learning disability. However, there can be difficulties for people with PMLD accessing mental health services, and little is known about effective psychological therapy for people with PMLD. Previous research has not considered carers perspectives in relation to this.

**Aims:** (i) To explore carers' experience of seeking support for their loved one with a profound and multiple learning disability's emotional difficulties; (ii) carers' experiences of working alongside professionals to establish helpful and unhelpful strategies in the treatment of their offspring's mental health problems; and (iii) carers' views about ways of making psychological treatments, in particular behavioural activation more accessible for people with PMLD.

**Methods:** It is hoped that 6-10 carers will be recruited from PAMIS voluntary organisation, that supports people with profound and complex needs and their families. There is a PAMIS branch in Inverness, and branches in Glasgow and Dundee. Carers must look after an individual over the age of 18 with a profound and multiple learning disability, and must have sought help for the individual with PMLD's emotional difficulties. The researcher will go along and speak at a PAMIS meeting to relevant families to provide information about the study, and will prepare a participant information sheet. Carers interested in taking part will be contacted by the researcher to arrange an appointment for interview at their convenience. The opportunity to ask further questions will be available to participants before being asked to provide informed consent to take part in the study. Participants will take part in one semi-structured interview with the researcher. This will be recorded and then transcribed and the researcher will remove any information, which may identify the participant or anyone that they talk about during the interview. The transcripts will be analysed using Interpretative Phenomenological Analysis. This is a qualitative method, which aims to explore people's experience of significant events.

**Ethical Issues:** Participants will be told that their participation is voluntary and confidential. The researcher will remind the participant that they can take a break or stop the interview and remove

consent to taking part in the study at any time without needing to provide a reason.  Information obtained during participant interviews will be stored in a secure locked filing cabinet.

**Practical Applications and Dissemination:** This research may help to inform more appropriate service provision and the adaptation of psychological therapies for individuals with PMLD.

*Proposal Appendix 2*

**Equipment Cost form**

### RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES

**Year of Course:**  2nd Year          **Intake Year**: 2015

Please refer to latest stationary costs list (available from student support team)

| Item | Details and Amount Required | Cost or Specify if to Request to Borrow from Department |
|---|---|---|
| Stationary | None | Subtotal: £0 |
| Postage | Freepost standard x 20<br><br>Envelopes x 20<br><br>Labels x 20 | £0.55 x 20 = £11<br><br>£1.84<br><br>£2.50<br><br><br>Subtotal: £15.34 |
| Photocopying and Laser Printing **(includes cost of white paper)** | Printing participant information sheets - 2 pages (double sided) x 30<br><br>Printing consent form – 1 page x 10 | £6.00<br><br>Subtotal: £6.00 |
| Equipment and Software | 1 digital voice recorder and transcribing kit | To be borrowed from the University of Glasgow.<br><br>Subtotal: £0 |
| Measures | None | Subtotal: £0 |
| Miscellaneous | Travel costs –<br><br>Return train fare Inverness to Glasgow x 2 = £80<br><br>Return train fare Inverness to Dundee x 2= £60 | £80<br><br>£60<br><br>Subtotal: £140 |
| **Total** | | £161.34 |

**For any request over £200 please provide further justification for all items that contribute to a high total cost estimate. Please also provide justification if costing for an honorarium:**

Trainee Signature:                              Date: 30/01/2017

Supervisor's Signature ………………………….…...        Date ………………………

*Proposal Appendix 3*

**Health and Safety Form**
**WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW**
**DOCTORATE IN CLINICAL PSYCHOLOGY**

**HEALTH AND SAFETY FOR RESEARCHERS**

| | |
|---|---|
| 1. Title of Project | Mental Health and Profound and Multiple Learning Disability |
| 2. Trainee | |
| 3. University Supervisor | Dr. Andrew Jahoda |
| 4. Other Supervisor(s) | |
| 5. Local Lead Clinician | |
| 6. Participants: (age, group or sub-group, pre- or post-treatment, etc) | Carers of adults with profound and multiple learning disabilities will be recruited from PAMIS, a voluntary organisation that provides support for people with PMLD, their family and carers. It is hoped that between 6-10 participants will be recruited for this study. |
| 7. Procedures to be applied (eg, questionnaire, interview, etc) | The researcher will speak at a PAMIS group meeting to relevant families to provide information about the study. The researcher will prepare a participant information sheet, including a study opt-in form. Interested participants will have an opportunity to ask any questions before giving written consent. Potential participants will take part in one semi-structured interview lasting 1-1.5 hours, which will be recorded using a voice recorder. Interviews will be transcribed and the content of the interviews will be explored and analysed to identify recurring themes using Interpretative Phenomenological Analysis. |

| 8.  Setting (where will procedures be carried out?)  i) Details of all settings | Interviews will be conducted by the researcher within PAMIS offices or public buildings used by PAMIS. |
|---|---|
| ii) Are home visits involved | No |
| 9.  Potential Risk Factors Considered (for researcher and participant safety):  i) Participants  ii) Procedures  iii) Settings | (i) This participant sample is not normally associated with dangerous or unpredictable behaviour.  (i) Frustration or distress due to sensitivity of the interview topic for participants.  (ii) Minimal risk to researcher and participant, adequate for the proposed study. |
| 10..  10. Actions to minimise risk (refer to 9)  i) Participants  ii) Procedures  iii) Settings | (i) All interviews will take place within normal working hours. Other staff will be aware when participants are being interviewed and will be available if required.  (ii) Given the sensitive nature of the interview topic, participant will be made aware that the researcher recognises and is seeking their expert knowledge of their family member with PMLD. The researcher will remind the participant that they can take a break or stop the interview and remove consent to the study at any time without needing to provide a reason. The researcher will do frequent 'check-ins' with participant to check for fatigue or distress and ensure they are happy to continue. If carer discloses information related to risk to self or others, researcher will act appropriately, respecting limits of confidentiality. If psychological difficulties become apparent, this will be discussed with carer and they will have option of asking for a referral to be made to adult mental health psychology services.  (iii) All interviews will comply with local standard safety procedures. |

Trainee signature:								Date: 30/01/2017

University supervisor signature: ............................................................. 	Date:.................................