THE UNIVERSITY OF HULL

Changing Perceptions of Adults with Intellectual Disabilities from Multiple Perspectives

being a Thesis submitted in partial fulfillment of the requirements for the degree of Doctor of Clinical Psychology in the University of Hull

by

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BSc (Hons) Psychology
University of York

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Acknowledgements

First and foremost, I would like to thank the theatre company for inviting me into their “family” with open arms (quite literally!). Your support during all aspects of the project has been incredibly valuable, and made this process much easier. I have also been inspired by the selfless work you do, and your modesty. I’m not sure you think the organisation does that much for people, but I hope this might change your mind.

I would like to thank Nick, for his on-going reassurance that everything is going to be okay, even when things felt the opposite. I would also like to thank the research team, to Tim, for his organisation, clarity and speedy email replies that kept anxiety at bay, and to Lesley, for talking me through lots of things about knowing, but never really knowing, but knowing that’s okay, because do we ever really know? (my brain is still hurting…)

I would also like to thank my family, for always accepting that I was “doing my work”, but never being quite sure what that meant. To my friends, for offering words of encouragement and being the non-psychologists we all need in our lives. To my partner, for navigating the near meltdowns, reminding me that things can wait until the morning, and being so chilled out that it couldn’t help but wear off on me.

Finally, I would like to thank myself three years ago, for knowing what interests me and I am passionate about before I even had the words for it.
Overview

This thesis portfolio comprises of three parts:

Part one – Systematic Literature Review

The systematic literature review explored the effectiveness of interventions to change negative perceptions of adults with intellectual disabilities. A systematic search identified 19 studies detailing various interventions. A narrative synthesis of the findings is presented, incorporating methodological critique throughout. Conclusions from the evidence base are drawn, with implications for future research.

Part two – Empirical Paper

The empirical paper explored the impacts of a theatre company on perceptions and understandings of intellectual disabilities from multiple perspectives including; members of the theatre company with intellectual disabilities, significant people in their lives, and members of the wider community. A qualitative approach was adopted, particularly thematic analysis. Four superordinate and nine subordinate themes were identified, acknowledging the connectivity, normality and growth associated with the theatre company, and offering recommendations for similar organisations. The findings are discussed relative to theoretical and empirical literature, culminating in implications of the results and avenues for future research.

Part three - Appendices

The appendices provide supplementary information for parts one and two, and also includes an epistemological statement and a reflective statement.

Total word count (excluding appendices): 15,552
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>2</td>
</tr>
<tr>
<td>Overview</td>
<td>3</td>
</tr>
<tr>
<td>Contents</td>
<td>4</td>
</tr>
<tr>
<td>List of tables and figures</td>
<td>6</td>
</tr>
</tbody>
</table>

**Part one – Systematic Literature Review**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title page</td>
<td>8</td>
</tr>
<tr>
<td>Abstract</td>
<td>9</td>
</tr>
<tr>
<td>Introduction</td>
<td>10</td>
</tr>
<tr>
<td>Method</td>
<td>14</td>
</tr>
<tr>
<td>Results</td>
<td>18</td>
</tr>
<tr>
<td>Discussion</td>
<td>36</td>
</tr>
<tr>
<td>References</td>
<td>45</td>
</tr>
</tbody>
</table>

**Part two – Empirical Paper**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title page</td>
<td>59</td>
</tr>
<tr>
<td>Abstract</td>
<td>60</td>
</tr>
<tr>
<td>Introduction</td>
<td>61</td>
</tr>
<tr>
<td>Method</td>
<td>66</td>
</tr>
<tr>
<td>Results</td>
<td>76</td>
</tr>
<tr>
<td>Discussion</td>
<td>92</td>
</tr>
<tr>
<td>References</td>
<td>102</td>
</tr>
</tbody>
</table>

**Part three – Appendices**

*Appendix 1.* Author guidelines for ‘Journal of Applied Research in Intellectual Disabilities’ (systematic literature review).


*Appendix 4.* Quality checklist ratings for all reviewed studies.

*Appendix 5.* Data extraction form.
<table>
<thead>
<tr>
<th>Appendix</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Author guidelines for ‘Journal of Community Psychology’ (empirical paper)</td>
<td>140</td>
</tr>
<tr>
<td>7</td>
<td>Documentation of ethical approval.</td>
<td>150</td>
</tr>
<tr>
<td>8</td>
<td>Recruitment flyer for PwID.</td>
<td>151</td>
</tr>
<tr>
<td>9</td>
<td>Recruitment flyer for significant others and community members.</td>
<td>152</td>
</tr>
<tr>
<td>10</td>
<td>Participant information sheet for members with ID.</td>
<td>153</td>
</tr>
<tr>
<td>11</td>
<td>Participant information sheet for members with ID – easy-read version.</td>
<td>158</td>
</tr>
<tr>
<td>12</td>
<td>Participant information sheet for significant others.</td>
<td>163</td>
</tr>
<tr>
<td>13</td>
<td>Participant information sheet for community members.</td>
<td>168</td>
</tr>
<tr>
<td>14</td>
<td>Consent form for members with ID.</td>
<td>173</td>
</tr>
<tr>
<td>15</td>
<td>Consent form for members with ID – easy-read version.</td>
<td>174</td>
</tr>
<tr>
<td>16</td>
<td>Consent form for significant others and community members.</td>
<td>175</td>
</tr>
<tr>
<td>17</td>
<td>Demographic information sheet for members with ID.</td>
<td>176</td>
</tr>
<tr>
<td>18</td>
<td>Demographic information sheet for significant others.</td>
<td>178</td>
</tr>
<tr>
<td>19</td>
<td>Demographic information sheet for community members.</td>
<td>180</td>
</tr>
<tr>
<td>20</td>
<td>Interview schedule for members with ID.</td>
<td>182</td>
</tr>
<tr>
<td>21</td>
<td>Visual aid of emotions for interviews.</td>
<td>183</td>
</tr>
<tr>
<td>22</td>
<td>Focus group schedule for significant others.</td>
<td>184</td>
</tr>
<tr>
<td>23</td>
<td>Focus group schedule for community members.</td>
<td>186</td>
</tr>
<tr>
<td>24</td>
<td>Sources of support form for members with ID.</td>
<td>188</td>
</tr>
<tr>
<td>25</td>
<td>Sources of support form for significant others and community members.</td>
<td>189</td>
</tr>
<tr>
<td>26</td>
<td>Worked example of analysis.</td>
<td>190</td>
</tr>
<tr>
<td>27</td>
<td>Epistemological statement.</td>
<td>196</td>
</tr>
<tr>
<td>28</td>
<td>Reflective statement.</td>
<td>203</td>
</tr>
</tbody>
</table>
List of Tables and Figures

**Part one – Systematic Literature Review**

- Figure 1. Flowchart detailing selection of studies for review. 19
- Table 1. Overview of reviewed studies. 22

**Part two – Empirical Paper**

- Table 1. Theatre members’ demographics. 69
- Table 2. Significant others’ demographics. 71
- Table 3. Community members’ demographics. 73
- Table 4. Overview of superordinate and subordinate themes. 76

**Part three - Appendices**

- Table 1. Breakdown of quality assessment ratings for qualitative studies. 135
- Table 2. Breakdown of quality assessment ratings for quantitative studies. 136
Part one: Systematic Literature Review
The effectiveness of interventions to change negative perceptions of adults with intellectual disabilities: a systematic review.

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This paper is written in the format ready for submission to the Journal of Applied Research in Intellectual Disabilities (see Appendix 1 for submission guidelines).

Total word count (excluding tables, figures and references): 7061
Abstract

Background: Negative perceptions of adults with intellectual disabilities (ID) are widely held, leading to social exclusion and discrimination. Various interventions to change negative perceptions have been implemented.

Method: This systematic review assesses the effectiveness of 19 contact, indirect contact and non-contact interventions to change perceptions of adults with ID, incorporating formal assessments of quality.

Results: Due to design and methodological limitations, the evidence base is not robust enough to support the efficacy of one intervention type over others. This contrasts with other reviews highlighting the effectiveness of contact and educational interventions in changing attitudes.

Conclusions: Possible explanations for this discrepancy are explored, and clear recommendations for future studies to establish the effectiveness of interventions to change perceptions of adults with ID are provided. Standardising measurement of perception change, including the use of follow-up and behavioural change measures appear priorities for future research.

Key words: Intellectual disabilities; perceptions; attitudes; interventions
Introduction

Intellectual disabilities (ID) are defined by three key criteria: A lessened intellectual ability, difficulties with adaptive behaviour and onset before the age of 18 (British Psychological Society (BPS), 2015). Historically, attitudes towards and perceptions of people with intellectual disabilities (PwID) have largely been negative (Munyi, 2012). An attitude is a response to something, and the tripartite model suggests attitudes are comprised of emotional, behavioural and cognitive components (Breckler, 1984). Thus, attitudes incorporate how people respond emotionally to, what they think about and how they act towards PwID. Furthermore, perceptions in this context refer to how people understand and interpret ID (Perception, 2017).

Earlier perceptions of PwID were of the ‘feeble-minded’, considered dangerous criminals that needed to be segregated (Hall, 2008). Later images were of the ‘eternal child’, suggesting PwID should be sheltered from experiencing ‘normal’ adulthood including living independently, being employed and having intimate relationships (Chappell, 1998; Scior, 2003; Flynn & Russell, 2005), because they were deemed vulnerable and incapable of these things (Goward & Gething, 2005). The negative impacts of such perceptions upon the self-esteem, confidence and emotional wellbeing of PwID are well established (Shessel & Reiff, 1999; Goodley, 2001; Scior, 2003). Previously, these perceptions meant PwID were indefinitely placed in institutions for their own and the public’s protection (Akrami, Ekehammar, Claesson & Sonnander, 2006). However, the deinstitutionalisation movement gained momentum in the 1980s and realised the government’s driver towards community care (Langan, 1990). This also coincided with the advent of the ‘social model of disability’ in 1983, highlighting the importance of the interaction between the individual and their environment, rather than
ID being solely intrinsic to the person because they were in some way ‘defective’ (Schalock et al, 1994; Dudley-Marling, 2004).

Thus, community integration and a new understanding of ID have led to increased acceptance and positive self-reported attitudes towards PwID within society (Emerson & Hatton, 1996; Ouellette-Kuntz, Burge, Brown & Arsenault, 2009). However, recent reviews highlight there is still limited understanding of ID amongst the public, a desire to maintain social distance from PwID and continued difficulties around social integration, despite a now physical presence (Cummins & Lau, 2003; Scior, 2011; Mencap, 2016). Furthermore, perception changes have not translated into increased opportunities for PwID, frequently being excluded from employment, social relationships and leisure activities (Verdonschot, de Witte, Reichrath, Buntinx & Curfs, 2009). Additionally, there has been a recent rise in the level of hate crime and abuse experienced by PwID (Home Office, 2016), linked to a broader rise in discrimination against marginalised groups following the European Union Referendum (Stop Hate UK, 2017). Overall, despite reports of increased positivity towards PwID within society, negative attitudes and exclusion still very much exist.

Various interventions to change perceptions of PwID have been implemented over time. Historically, participants’ attitudes were measured before and after visits to institutions, providing varying results of efficacy (Carsrud et al, 1984). The premise of this and subsequent interventions is based upon Allport’s (1954) contact theory. This states contact between two groups can reduce negative attitudes providing four conditions are satisfied: the groups are of equal status; there is joint effort towards a common goal; there is some cooperation between the groups; and authorities and institutions support the contact. However, Pettigrew and Tropp’s (2006) meta-analysis of interventions
based upon contact theory highlighted how these factors are interdependent, and also these conditions are not vital to produce attitude change. Thus, there is still controversy surrounding what makes an effective intervention to change attitudes.

Donaldson’s (1980) review of interventions to change attitudes towards people with intellectual and physical disabilities went some way to identify what constitutes efficacious interventions in this context. Effective components identified included the person with a disability being of equal status to the person without a disability with whom they were in contact with, similar to one of Allport’s (1954) conditions, and also the person with a disability not acting ‘stereotypically’. Moreover, Donaldson (1980) suggested structured interventions were more effective than unstructured, and also that brief interventions could produce attitude change. However, this review was conducted before the social model of disability (Schalock et al., 1994) and encompassed both intellectual and physical disabilities. Thus, later reviews have separated out intellectual and physical disabilities, acknowledging the distinct perceptions linked to the former (e.g. Scior, 2011) and latter (e.g. Satchidanand et al., 2012).

Scior’s (2011) review predominantly brought together literature around public attitudes towards PwID, but also alluded to interventions to change these attitudes. The review highlighted limitations of the evidence base including limited use of repeated measures designs and small, unrepresentative samples. Nonetheless, the importance of ensuring contacts where participants have positive rather than negative experiences of PwID was emphasised, as the latter was thought to have potential detrimental impacts. A later review around interventions to change attitudes among lay people towards PwID equally acknowledged methodological limitations of the evidence base, and also highlighted problems with instruments to measure attitude change (Seewooruttun &
Scior, 2014). However, the importance of contact with PwID was similarly highlighted, particularly through delivering interventions themselves. Moreover, educational interventions were promoted. Finally, Scior and Werner’s (2015) non-systematic review for Mencap drew similar conclusions to the other recent publications, and added further drawbacks of the literature to include limited understanding of whether attitude change equates to behavioural change towards PwID.

In summary, the more recent reviews have focused upon interventions to change attitudes towards PwID amongst a lay population, and highlighted the importance of contact and educational components in effective interventions. Despite acknowledging design and methodological limitations, a review is yet to incorporate formal quality assessments.

Hence, the rationale for this review is to consider the evidence base more broadly, going beyond attitudes towards PwID to also consider changes in perceptions following interventions with a wider demographic than a lay population. However, this review will be limited to interventions to change negative attitudes and perceptions of adults with ID, as these perceptions are linked to societal problems more relevant to adults than children, including exclusion from employment, independent living, and romantic relationships (e.g. Scior, 2003). PwID will now refer to adults with ID throughout. Finally, formal quality assessments will be incorporated, to offer a more structured and rigorous approach to considering the design and methodological limitations highlighted in previous reviews. Such a review appears key in preventing the widespread exclusion of and discrimination against PwID.
Aim of the review

The aim of this review is to establish the effectiveness of interventions to change negative perceptions of adults with ID, formally assessing the quality of intervention studies.

Method

Search Strategy

A systematic search was conducted between October 2016 and May 2017 utilising the following computerised databases: PsycINFO, PsycARTICLES, MEDLINE, CINAHL, ERIC, Education Research Complete, Academic Search Premier and Web of Science. This included both subject-specific and broader databases to ensure breadth of the literature captured.

The following search strategy was employed utilising key terms for ID used currently and in the past identified from initial database searches. Key terms around perceptions and interventions were also inputted, with a near operator to ensure changing perceptions was the focus of the literature retrieved:

“learning disab*” OR “learning difficult*” OR “learning disorder*” OR “intellectual* disab*” OR “intellectual* difficult*” OR “intellectual* impair*” OR “intellectual* disorder*” OR “mental* disab*” OR “mental* retard*” OR “mental* handicap*” OR “mental* impair*” OR “mental* subnorm*” OR “mental* deficien*” OR “developmental* disturb*” OR “developmental* disab*” OR “develop* delay*” OR “cognitiv* disab*” OR “cognitiv* difficult*” OR “cognitiv* delay*”
AND

(idea* OR perception* OR aware* OR belie* OR opinion* OR knowledge* OR understand* OR stigma* OR attitude* OR view* OR prejudice* OR expectation*) N3 (NEAR/3 on Web of Science) (challeng* OR chang* OR alter* OR modif*)

AND

interven* OR approach* OR program* OR campaign* OR strateg*

Initially, papers were reviewed by title and abstract to assess their relevance. The full papers of relevant studies were then read, and the exclusion criteria below applied. Additionally, the reference lists of the three recent, related reviews (Scior, 2011; Seewooruttun & Scior, 2014; Scior & Werner, 2015) and of all included articles were hand-searched. The same process from reviewing the title and abstract to full paper was applied.

Exclusion criteria

Articles were not included if they:

1. Were not published in the English language due to time and financial constraints around translation.
2. Were not peer-reviewed to ensure quality control of evidence.
3. Appeared as literature reviews or books, as the review sought primary sources of evidence.
4. Were published before 1983, as the conceptualisation of ID from a social perspective emerged after this time (Schalock et al, 1994).
5. Did not focus upon changing perceptions of PwID, as the societal problems guiding this review e.g. lack of employment or opportunities to live independently (Scior, 2003) are more linked to negative perceptions of adults than children. Studies involving both adults and children with ID were excluded if the data sets could not be separated including studies regarding the Special Olympics (e.g. Roper, 1990), institutional tours (Carsrud et al, 1984) and an intervention series at the Leros PIPKA asylum (e.g. Tsiantis, Diareme & Kolaitis, 2000). Moreover, articles were excluded if the contact component of the intervention was only with children with ID (e.g. Kobe & Mulick, 1995).

6. Did not specifically focus on ID, and included disabilities and difficulties where ID are not always present. Examples included Autism Spectrum Conditions (May, 2012), developmental disabilities such as cerebral palsy, traumatic brain injuries (Anderson, Schleien, McAvoy, Lais & Seligmann, 1997) and mental health problems (e.g. Berryman, Evans & Kalbag, 1994).

7. Focused upon changing perceptions in a highly specific domain rather than perceptions more broadly e.g. changing attitudes towards conducting eye examinations on PwID (Adler, Cregg, Duignan, Ilett & Woodhouse, 2005).

8. Did not implement an intervention to change perceptions and observed attitude change based on something already happening e.g. the impact on neighbours of someone with ID living next door (van Alphen, Dijker, van den Borne & Curfs, 2010).

Both quantitative and qualitative studies were included to reflect various operationalisations of perception change. Participants from all age ranges and settings were included, as the literature does not suggest negative perceptions of PwID are limited to certain societal groups (Scior, 2011).
Quality Assessment

Each included study was quality checked using the relevant National Institute for Health and Care Excellence (NICE) checklist – qualitative (Appendix 2) or quantitative (Appendix 3) (NICE, 2012). Other checklists designed to evaluate the quality of interventions were considered (e.g. Downs & Black, 1998). However, such tools are geared towards assessing the quality of quantitative studies, so the NICE checklists were chosen to reflect the various methodologies included. Furthermore, these complimentary tools provided a consistent rating framework that could be applied across qualitative and quantitative studies, and enabled comparison across the literature base overall. One study used a mixed methods design (Sinson & Stainton, 1990), but as only the qualitative part related to perception change, the qualitative checklist was used to assess this study.

Six articles were quality checked by a peer reviewer. These were articles the researcher found particularly difficult to review, as consistency in ratings across these articles would suggest broader reliability. If there was a discrepancy in ratings, both reviewers provided a rationale for their rating referring back to the original study, and reached a final decision collaboratively. The quality rating of each study is presented in Table 1 (Appendix 4 provides a breakdown of the quality assessment ratings). Papers were not excluded based upon their methodological quality as the review aimed to bring together all intervention studies, and any commonly occurring design and methodological limitations would be enlightening about the evidence base overall.

Data Extraction and Synthesis

Data was systematically extracted from the articles using a bespoke form created specifically to gather information relevant to the review (Appendix 5). Statistical
methods of data synthesis were not feasible, due to the mixed methodologies and diversity of included studies. Therefore, a narrative synthesis was used to collate the evidence, seeking to tell the story of included studies using text, and to draw conclusions about the evidence base overall (Popay et al, 2006). This involved moving between: Considering the effectiveness of interventions relative to intervention type and participant group; Organising the findings in a meaningful way; Exploring relationships between findings; and assessing the robustness and trustworthiness of the synthesised findings, based upon the methodological quality of the evidence base overall (Popay et al, 2006).

Results

Details of included and excluded studies

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher, Liberati, Tetzlaff & Altman, 2009) process was followed to identify articles for inclusion (Figure 1). The search strategy retrieved 1849 articles, limited to 948 when papers not published in English and duplicates were removed. Of those, 870 were deemed irrelevant by title and abstract, leaving 78, of which 66 were excluded based upon the full paper review, leaving 12 articles identified from the electronic databases. A further three studies were identified through hand-searching the reference lists of the three related reviews, and four studies through the reference lists of the included articles, producing a final total of 19 papers for inclusion in this review. This included 15 quantitative studies, three qualitative studies and one mixed methods design.
Table showing database search results:

<table>
<thead>
<tr>
<th>Database</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL</td>
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</tr>
<tr>
<td>PsycINFO</td>
<td>415</td>
</tr>
<tr>
<td>PsycARTICLES</td>
<td>8</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>216</td>
</tr>
<tr>
<td>ERIC</td>
<td>180</td>
</tr>
<tr>
<td>Education Research Complete</td>
<td>282</td>
</tr>
<tr>
<td>Academic Search Premier</td>
<td>377</td>
</tr>
<tr>
<td>Web of Science</td>
<td>266</td>
</tr>
</tbody>
</table>

Diagram:

- Database Search (Conducted on 24/10/2016)
- CINAHL (N= 105)
- PsycINFO (N= 415)
- PsycARTICLES (N= 8)
- MEDLINE (N= 216)
- ERIC (N= 180)
- Education Research Complete (N= 282)
- Academic Search Premier (N= 377)
- Web of Science (N=266)

Flowchart:

1. Total (N= 1849)
2. English language limiter (N= 53)
3. Total (N= 1796)
4. Duplicates (N= 848)
5. Total (N= 948)
6. Irrelevant title and abstract (N= 870)
7. Total (N= 78)
8. Irrelevant full paper (N= 65)
9. Total (N= 13)
10. Replication of same data (N= 1)
11. Total (N= 12)
12. Papers identified from hand-searching reference lists of related reviews (N= 3)
13. Total (N= 15)
14. Papers identified from hand-searching reference lists of included articles (N= 4)
15. Final total (N= 19)

*Figure 1. Flowchart detailing article selection process.*
Overview of included studies

Table 1 provides an overview of the 19 studies reviewed. Articles used various terminologies to describe ID, but ID is used throughout this review to reflect the internationally accepted term (BPS, 2015).

The majority of studies were conducted in the UK, 12, whilst two were carried out in both the USA (Russell & Ayer, 1988; Nosse & Gavin, 1991) and Canada (Hall & Minnes, 1999; Jones, McQueen, Lowe, Minnes & Rischke, 2015), and one in each of Australia (Sheilds & Taylor, 2014), Ireland (McConkey, McCormack & Naughton, 1983) and the Balearic Islands (de la Iglesia Mayol, 2006).

Various interventions to change perceptions of PwID were reported including 10 involving direct contact with PwID, nine as part of an educational/training course and one as part of a programme to house and entertain PwID (Nosse & Gavin, 1991). Four interventions involved indirect contact with PwID through viewing pictures (Varughese & Luty, 2010; Varughese, Mendes & Luty, 2011) or films (Hall & Minnes, 1999; Walker & Scior, 2013), and five involved no contact with PwID, including three training programmes (Bailey, Barr & Bunting, 2001; de la Iglesia Mayol, 2006; Sinai, Strydom & Hassiotis, 2013) and two written information interventions (Russell & Ayer, 1988; Sinson & Stainton, 1990).

Included studies also attempted to change perceptions amongst various participant groups. Four interventions were implemented with the general public (Sinson & Stainton, 1990; Varughese & Luty, 2010; Varughese et al, 2011; Walker & Scior, 2013), three with university students (Nosse & Gavin, 1991; Hall & Minnes, 1999; Smith & Forrester-Jones, 2014) and one with senior school students (McConkey et al,
Interventions were also conducted with people working with PwID, including two with professionals (de la Iglesia Mayol, 2006; Jones et al, 2015), and seven with students training in professions to work with PwID including five interventions with medical students (Laking, 1988; May, 1991; May et al, 1994; Hall & Hollins, 1996; Sinai et al, 2013), one with physiotherapy students (Sheilds & Taylor, 2014), and one with ID nursing students (Mee, 2010). One intervention was conducted with police officers (Bailey et al, 2001), and one with industrial managers (Russell & Ayer, 1988).

Overview of design and methodology

Of the quantitative studies, 10 used validated and replicated measures of attitude change, whilst five used questionnaires designed for the study (McConkey et al, 1983; May, 1991; May et al, 1994; Hall & Hollins, 1996; Jones et al, 2015). Eight studies used a repeated measures design, whilst seven had no control group (May, 1991; Hall & Hollins, 1996; Varughese et al, 2011; Sinai et al, 2013; Walker & Scior, 2013; Shields & Taylor, 2014; Jones et al, 2015). Eleven studies measured perceptions pre- and post-intervention, whilst four only measured attitudes post-intervention (Laking, 1988; Hall & Minnes, 1999; Varughese & Luty, 2010; Varughese et al, 2011). Only two studies measured whether attitude change was maintained over time, both after a four-week period (McConkey et al, 1983; Walker & Scior, 2013). Only one of the three qualitative studies and one mixed methods design employed a formal qualitative analysis (Smith & Forrester-Jones, 2014).
Table 1. Overview of included studies. (Descriptors for quality ratings (NICE, 2012): ++ = all or most of checklist criteria achieved; + = some criteria achieved and missed criteria unlikely to alter conclusions; - = few or no criteria achieved and likely to alter conclusions).

<table>
<thead>
<tr>
<th>Author, Year &amp; Location</th>
<th>Participants</th>
<th>Design</th>
<th>Intervention(s)</th>
<th>Measure(s) used</th>
<th>Findings</th>
<th>NICE Quality rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bailey, Barr &amp; Bunting (2001) (Northern Ireland, UK)</td>
<td>27 trainee police officers (no demographic information)</td>
<td>Quantitative</td>
<td>Non-contact</td>
<td>Attitudes toward Mental Retardation and Eugenics (AMRE) SCALE (Antonak, Fielder &amp; Mulick, 1993)</td>
<td>Effective</td>
<td>+</td>
</tr>
<tr>
<td>de la Iglesia Mayol (2006) (Balearic Islands)</td>
<td>13 professionals (no demographic information)</td>
<td>Qualitative</td>
<td>Non-contact</td>
<td>Interviews</td>
<td>Reported as effective, but no qualitative analysis conducted</td>
<td>-</td>
</tr>
<tr>
<td>Hall &amp; Hollins (1996) (London, UK)</td>
<td>28 medical students (no demographic information)</td>
<td>Quantitative</td>
<td>Contact</td>
<td>Rated agreement with 10 statements about people with Down Syndrome</td>
<td>Effective</td>
<td>-</td>
</tr>
<tr>
<td>Hall &amp; Minnes (1999) (Canada)</td>
<td>92 psychology undergraduates 41 male (m), 51 female (f) Mean age = 19.6</td>
<td>Quantitative</td>
<td>Indirect contact</td>
<td>Modified Attitude to Disabled Persons (ATDP) Scale (Yuker, Block &amp; Young, 1970)</td>
<td>Effective</td>
<td>+</td>
</tr>
<tr>
<td>Author, Year &amp; Location</td>
<td>Participants</td>
<td>Design</td>
<td>Intervention(s)</td>
<td>Measure(s) used</td>
<td>Findings related to intervention effectiveness</td>
<td>NICE Quality rating</td>
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<tr>
<td>Jones, McQueen, Lowe, Minnes &amp; Rischke (2015) (Canada)</td>
<td>247 graduates from healthcare professions (no demographic information)</td>
<td>Quantitative</td>
<td>Non-contact</td>
<td>Modified Comfort Scale (Marcotte &amp; Minnes, 1989)</td>
<td>Volunteering intentions scale</td>
<td>Ineffective +</td>
</tr>
<tr>
<td>Laking (1988) (London, UK)</td>
<td>33 medical students 18 m, 15 f</td>
<td>Quantitative</td>
<td>Contact</td>
<td>ATDP Scale (Yuker, Block &amp; Campbell, 1960) (changed ‘disabled’ to ‘mentally handicapped’)</td>
<td>Ineffective +</td>
<td></td>
</tr>
<tr>
<td>McConkey, McCormack &amp; Naughton (1983) (Dublin, Ireland)</td>
<td>Study 1 – 197 senior school students Study 2 – 368 students 25% m, 75% f</td>
<td>Quantitative</td>
<td>Contact</td>
<td>3 idiosyncratic questionnaires</td>
<td>Mixed results +</td>
<td></td>
</tr>
<tr>
<td>Author, Year &amp; Location</td>
<td>Participants</td>
<td>Design</td>
<td>Intervention(s)</td>
<td>Measure(s) used</td>
<td>Findings related to intervention effectiveness</td>
<td>NICE Quality rating</td>
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<tr>
<td>May (1991) (Dundee, UK)</td>
<td>26 medical students 17 m, 9 f</td>
<td>Quantitative</td>
<td>Contact</td>
<td>Idiosyncratic questionnaire</td>
<td>Ineffective</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pre- and post-intervention measures</td>
<td>Educational course involving placements with PwID</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>May et al (1994) (Dundee, UK)</td>
<td>23 medical students (no demographic information)</td>
<td>Quantitative</td>
<td>Contact</td>
<td>Idiosyncratic questionnaire</td>
<td>Mixed results</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pre- and post-intervention measures</td>
<td>Educational course involving placements with PwID and collaboration on tasks</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Comparison to 1990 cohort in May (1991)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Mee (2010) (Lancaster, UK)</td>
<td>26 students on ID nursing course</td>
<td>Qualitative</td>
<td>Contact</td>
<td>Idiosyncratic questionnaire</td>
<td>Reported as effective, but no qualitative analysis conducted</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Post-intervention measure</td>
<td>Hearing oral histories of PwID</td>
<td></td>
<td></td>
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<tr>
<td>Author, Year &amp; Location</td>
<td>Participants</td>
<td>Design</td>
<td>Intervention(s)</td>
<td>Measure(s) used</td>
<td>Findings related to intervention effectiveness</td>
<td>NICE Quality rating</td>
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<tr>
<td>Nosse &amp; Gavin (1991) (Wisconsin, USA)</td>
<td>31 college students 22.5% m, 77.5% f Mean age = 21</td>
<td>Quantitative</td>
<td>Contact</td>
<td>Adjective Generation Technique (AGT) (Allen &amp; Potkay, 1983)</td>
<td>Effective</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Pre- and post-intervention measures</td>
<td>Semantic differential scaling of bipolar adjectives (Gottlieb &amp; Corman, 1975; Horne, 1985)</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Housed and entertained PwID over 2.5 days</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Comparison to control group (n=23; 22% m, 78% f, Mean age = 22)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Pre- and post-intervention measures</td>
<td></td>
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<tr>
<td></td>
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<td></td>
<td>3 information leaflets about ID</td>
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<td></td>
<td></td>
<td>Comparison to control group (n=49)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Shields &amp; Taylor (2014) (Australia)</td>
<td>16 physiotherapy students 3 m, 13 f Mean age = 22.5</td>
<td>Quantitative</td>
<td>Contact</td>
<td>Discomfort subscale of the Interaction with Disabled Persons scale (Iacono,</td>
<td>Effective</td>
<td>++</td>
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<tr>
<td></td>
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<td>Pre- and post-intervention measures</td>
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<td></td>
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<td></td>
<td>8-week walking or social activity programme</td>
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<tr>
<td>Author, Year &amp; Location</td>
<td>Participants</td>
<td>Design</td>
<td>Intervention(s)</td>
<td>Measure(s) used</td>
<td>Findings related to intervention effectiveness</td>
<td>NICE Quality rating</td>
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<td></td>
<td>Measures completed pre- (n=136) and post-intervention (n=133) (both pre and post n=54)</td>
<td>Educational course</td>
<td></td>
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<tr>
<td>Author, Year &amp; Location</td>
<td>Participants</td>
<td>Design</td>
<td>Intervention(s)</td>
<td>Measure(s) used</td>
<td>Findings related to intervention effectiveness</td>
<td>NICE Quality rating</td>
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<tr>
<td>Sinson &amp; Stainton (1990) (UK)</td>
<td>254 members of general public 90 m, 160 f</td>
<td>Qualitative</td>
<td>Non-contact</td>
<td>Interviews</td>
<td>Ineffective</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Questionnaire pre- and interview post-</td>
<td>Information pack about ID</td>
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<td></td>
<td></td>
<td>intervention</td>
<td></td>
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<tr>
<td>Smith &amp; Forrester-Jones (2014) (UK)</td>
<td>62 social science students (no demographic information)</td>
<td>Qualitative – Interpretative Phenomenological Analysis (IPA)</td>
<td>Contact</td>
<td>Analysed themes from reflective journals</td>
<td>Effective</td>
<td>+</td>
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<td></td>
<td></td>
<td></td>
<td>Educational course 2-3 interviews with person with ID</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Kept reflective journals throughout intervention</td>
<td></td>
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<tr>
<td>Varughese &amp; Luty (2010) (UK)</td>
<td>360 members of the general public 26% m, 74% m Mean age = 47.9</td>
<td>Quantitative</td>
<td>Indirect contact</td>
<td>5-item Attitude to Mental Illness Questionnaire (AMIQ) (Cunningham, Sobell &amp; Chow, 1993; Luty, Fakuda, Umoh &amp; Gallagher, 2006)</td>
<td>Effective</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Post-intervention measure</td>
<td>Viewed picture of man with Down Syndrome dressed smartly in an office</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Comparison to control group – crossover design</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Varughese, Mendes &amp; Luty (2011) (UK)</td>
<td>‘Good’ photo group: 105 members of</td>
<td>Quantitative</td>
<td>Indirect contact</td>
<td>5-item AMIQ (Cunningham et al, 1993; Luty et al,</td>
<td>Effective – viewing ‘good’ photo</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Post-intervention</td>
<td>Viewed either</td>
<td></td>
<td></td>
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<tr>
<td>Author, Year &amp; Location</td>
<td>Participants</td>
<td>Design</td>
<td>Intervention(s)</td>
<td>Measure(s) used</td>
<td>Findings related to intervention effectiveness</td>
<td>NICE Quality rating</td>
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<tr>
<td></td>
<td>the general public 40% m, 60% f Mean age = 54</td>
<td>measures</td>
<td>‘good/attractive’ photo of person with Down Syndrome or ‘bad/unattractive’ photo</td>
<td>2006)</td>
<td></td>
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<tr>
<td></td>
<td>‘Bad’ photo group 82 members of the general public 46% m, 54% f Mean age = 51</td>
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</table>
Overview of findings

Interventions involving face-to-face contact

Positive results

Of the 10 interventions involving contact with PwID, results of effectiveness were variable. Hall and Hollins (1996) found a two-hour workshop delivered by PwID generated significantly more agreement with positive statements and significantly less agreement with negative statements about people with Down syndrome amongst medical students. However, the statements used to measure attitude change were developed for the study, and not shown to be valid or reliable. There was also a lack of repeated measures design, making it unclear if the positive findings specifically related to the workshop, or were due to another variable. This limitation was furthered by ambiguity around the source population medical students were recruited from and a small sample size, suggesting the findings may not be generalisable to similar groups. Furthermore, Mee (2010) found nursing students who heard the oral histories of PwID had more positive perceptions, and reported improvements in their professional practice. However, the limited information about the sample, data collection, and qualitative analysis opens the study to bias and lack of rigour. Therefore, the design and methodological limitations of these two studies, as supported by their poor quality ratings, makes it difficult to rely upon their positive findings about the effectiveness of these contact interventions.

Nonetheless, Smith and Forrester-Jones (2014) used reflective journals to monitor changes following social science students participating in a module about doing research with PwID, and conducting two/three interviews with a person with ID. They
found students made more positive reflections and expressed more positive attitudes about PwID as the module progressed. This was the only study identified in the review using formal qualitative analysis, and the richness of the data described and rigour of the analysis made the findings convincing. Furthermore, Shields and Taylor (2014) found physiotherapy students engaging in an eight-week physical or social activity programme with people with Down syndrome reported to feel more comfortable around PwID. The design and methodological strengths of this study included using multiple measures of attitude change, and attempting to minimise bias around intervention allocation. However, the students’ attitudes before the intervention were already positive, so negative perceptions were not changed to positive, but rather, positive attitudes made even more positive. This study also lacked a control group to compare findings against.

Additionally, Nosse and Gavin (1991) found college students who housed, entertained and participated in organised activities with PwID over 2.5 days were shown to perceive PwID significantly more favourably, feel significantly less anxious around them and rate PwID significantly more positively on bipolar adjective scales. Despite using a repeated measures design, the experimental group rated PwID significantly more favourably before the intervention, suggesting the experimental group were more inclined to respond positively towards PwID pre-intervention. This may relate to the experimental group being students in helping professions, whereas the control group were students mainly on business courses, suggesting unmatched groups initially.

**Negative results**

Other studies did not yield positive results. Both Laking (1988) and May (1991) found educational courses involving contact did not significantly impact upon the attitudes of
medical students towards PwID. Laking (1988) found no significant difference between scores on the ATDP (Yuker et al, 1960) of medical students who attended an educational course compared to controls. The discussion mentions medical students making more positive comments about PwID post-intervention with suggestions towards attitude change, but it is unclear how this data was collected, and represents data dredging rather than a positive finding. The small sample also makes the generalisability of these findings questionable. Furthermore, May (1991) found that following an educational course, medical students picked similar proportions of positive and negative adjectives to describe PwID, and when compared to words chosen to describe medical students, PwID were seen qualitatively differently i.e. that they were ‘affectionate’ and ‘happy’ whilst medical students were ‘intelligent’ and ‘hard-working’. Moreover, there were inconsistencies in what rights medical students thought PwID should have, and students did not want to work with PwID following the course. However, limitations of this study including a lack of repeated measures design, idiosyncratic measures and ambiguity around sampling and accountability for dropout make the conclusions that can be drawn limited.

Furthermore, Jones at al (2015) report similar findings with professionals from various backgrounds, finding no significant change in perceptions following a multi-component educational course involving contact with PwID. However, an idiosyncratic measure was used, including only three items that related to attitudes, and was not shown to be valid or reliable. Therefore, it is unclear whether perceptions did not change in this study, or whether the measure was not sensitive enough to detect such changes. Furthermore, professionals’ attitudes were reported to be neutral or positive before the intervention, so a lack of positive result may relate to their attitudes already being positive.
Mixed results

Two further studies report more varied results around the effectiveness of contact interventions. McConkey et al (1983) found senior school students who had contact with PwID as part of an educational programme showed significant increases in their confidence scores around PwID, both when the intervention was delivered by the study facilitators, and by volunteers and teachers. This suggests the effectiveness of the intervention was not due to factors related to the study facilitators. As one of only two studies identified using follow-up measures, McConkey et al (1983) found impacts upon confidence scores were only partially maintained after four weeks. Moreover, there was limited impact of the intervention on adjective ratings or beliefs about the community integration of PwID. This study again used idiosyncratic measures that were not shown to be valid or reliable. However, the use of a repeated measures design means the change in confidence scores can be attributed to the intervention effects.

Finally, May et al (1994) report a comparison to the 1990 cohort of medical students reported in May (1991), when improvements to the educational course were made. Collaborative working on a mutually interesting task with PwID changed self-reported attitudes, and more positively impacted on the words medical students chose to describe PwID, selecting significantly more positive adjectives. However, the words chosen were similar to those of the 1990 cohort (May, 1991), suggesting the medical students still saw PwID in a qualitatively different way to themselves. Moreover, there was no significant impact on what medical students believed were the rights of PwID, and they were not interested in working with PwID following the course. However, similar to May (1991), there is limited information around the sample, recruitment and accountability for dropout, and questions around the validity and reliability of idiosyncratic measures of attitude change.
Summary

In summary, interventions involving contact to change perceptions of PwID had varying results of efficacy. There are limited conclusions that can be drawn about the effectiveness of contact interventions overall, due to diversity of the interventions implemented, and the design and methodological limitations noted, namely the use of idiosyncratic measures and limited information around sampling.

Interventions involving indirect contact

Four studies report the effectiveness of interventions involving ‘indirect contact’ with PwID, where contact is mediated through media portrayal. Two studies involved viewing pictures of PwID. Varughese and Luty (2010) found participants who viewed a picture of a man with Down syndrome dressed smartly in an office reported significantly less stigmatised attitudes compared to those who read a description. Equally, those who viewed a ‘good/attractive’ photo of a person with Down syndrome compared to a ‘bad/unattractive’ photo reported significantly more positive attitudes towards PwID (Varughese et al, 2011). However, these studies only measured attitudes post-intervention, so it is unclear whether positive self-reported attitudes were due to viewing the photos, or unmatched groups initially. Moreover, although not formally measured, Varughese and Luty’s (2010) use of a random crossover trial inadvertently suggests the lack of long-term effectiveness of the intervention. The results of the experimental and control groups six months apart were combined, and so the experimental group acted as their own controls suggesting attitude changes were not maintained over time.

Two further studies involved indirect contact through film portrayal of PwID. Psychology undergraduates watched either a documentary or drama involving a young
male with Down syndrome (Hall & Minnes, 1999). Watching either film significantly predicted volunteering intentions, but those who watched the documentary were significantly more willing to volunteer and significantly more comfortable in situations with people with Down syndrome. However, similarly to the above studies, a lack of baseline data means it is difficult to draw conclusions around whether these findings relate to attitude changes following viewing the films, or are due to unmatched groups initially. Finally, Walker and Scior (2013) recruited members of the public to watch a film based on either intergroup contact theory or a protest message. Both films changed inclusion attitudes and social distance in the short-term, impacts partially maintained at one-month follow-up, but the protest message had a greater effect on some aspects of inclusion attitudes. However, despite using a large sample from the general public and numerous measures to monitor attitude change, this study is limited by lacking a control group, making it unclear if the positive findings are due to the intervention or another variable. Similarly to other studies, the baseline attitudes of participants were reported to be positive, echoing that the intervention did not necessarily change negative attitudes to positive, but made already positive attitudes more positive.

Summary

In summary, interventions involving indirect contact to change perceptions of PwID had promising results of efficacy. However, a lack of baseline data makes drawing firm conclusions difficult, and follow-up measures question the maintenance of such effects over time.
Interventions involving no contact

Positive results
A final group of interventions to change perceptions involved no contact with PwID. Russell and Ayer (1988) found three leaflets about ID posted to industrial managers positively changed their attitudes compared to a matched control group. The use of a repeated measures design, and a valid and reliable measure to monitor attitude change uphold the findings of this study. Moreover, Bailey et al (2001) found police officers attending a two-week training course about ID showed significantly less eugenic-based attitudes about PwID compared to controls. However, the nature of the two-week training course is unclear apart from one training event, so whether this intervention could be replicated and produce similar, positive results is questionable. Information about the source population of police officers is also limited.

Furthermore, de la Iglesia Mayol (2006) set up an interdisciplinary group of 13 professionals from varying backgrounds and engaged them in 10 training sessions to change attitudes. Positive comments about attitude change across the professionals were reported, particularly from one entrepreneur in the group. However, this study is limited by the lack of formal qualitative analysis, bias towards presenting the views of one participant over others, and insufficient information about the intervention. Therefore, due to lack of rigour and transparency, the poor quality of this study means the findings cannot be relied upon or considered valid.

Negative results
In contrast to these positive results, Sinson and Stainton (1990) found no change in members of the publics' attitudes following a written information intervention, and the
opportunity to meet children with ID and their families. However, this negative finding may relate to only 25% of the participants receiving, reading and remembering anything about the written information, and no participants making contact with a child with ID (hence inclusion in this review). Therefore, as only a minority of participants undertook the intervention, this negative result cannot be relied upon as an indication of intervention inefficacy. Nonetheless, Sinai et al (2013) found no impact of a three-hour lecture on ID on the attitudes of medical students towards PwID. However, limited information about the ‘14-week neurosciences block’ that participants undertook questions the reliability of the intervention, and there was also a lack of repeated measures design.

Summary

In summary, interventions involving no contact to change perceptions of PwID had varying results of efficacy. It is difficult to draw firm conclusions regarding effectiveness, namely due to limited information around the nature of interventions.

Discussion

Overview of findings

The aim of this review was to establish the effectiveness of interventions to change perceptions of adults with ID, incorporating formal assessments of study quality. The 19 studies reviewed involved various contact, indirect contact and non-contact interventions. Reports of effectiveness were variable, with design and methodological limitations noted throughout.
Of the 10 contact interventions, design and methodological limitations made conclusions that could be drawn from three studies limited (May, 1991; Hall & Hollins, 1996; Mee, 2010). Of the remaining seven articles, the only study using formal qualitative analysis found contact did improve attitudes (Smith & Forrester-Jones, 2014). Of the quantitative methodologies, two studies showed contact interventions made already positive attitudes even more positive (Nosse & Gavin, 1991; Shields & Taylor, 2014). Other studies reported no attitude change, but these were limited by the sensitivity of measures employed to detect such changes, stated by Laking (1988), and drawn out of the quality assessment for Jones et al (2015). Of the studies with mixed findings, contact interventions appeared to change how participants related to PwID, but not beliefs about their inclusion or attributes (McConkey et al, 1983; May et al, 1994).

The overall conclusions that can be drawn from these 10 studies is limited, due to the diversity of interventions and the design and methodological limitations noted. However, it is clear that measuring whether contact interventions change negative attitudes to positive through the use of valid, reliable and sensitive measures would strengthen this literature base.

All four studies regarding the effectiveness of indirect contact interventions reported positive results. The main limitation of studies in this area was a lack of baseline data (Hall & Minnes, 1999; Varughese & Luty, 2010; Varughese et al, 2011). Despite the methodological strengths of one intervention using films (Walker & Scior, 2013), this study was limited by having no control group. Moreover, the maintenance of changes from indirect contact interventions over time appeared limited, when formally measured (Walker & Scior, 2013) and informally inferred (Varughese et al, 2011). Overall, the conclusions that can be drawn about the effectiveness of indirect contact interventions are again limited by the design and methodological limitations noted. Studies in this
area would benefit from measuring perceptions pre- and post-intervention, and comparison to control groups.

Of the five non-contact interventions, the poor quality of the one qualitative study (de la Iglesia Mayol, 2006) meant the findings could not be relied upon. Moreover, the limited perception change reported by Sinson and Stainton (1990) may not indicate inefficacy of the intervention, due to the small number of participants engaging with the written information provided. Of the remaining three studies, both a written information intervention (Russell & Ayer, 1988) and a training course (Bailey et al, 2001) appeared to positively impact upon attitudes towards PwID without significant design or methodological limitations of these studies. However, Sinai et al (2013) report contradictory results of an educational course with medical students, but this may be due to less time focused on ID in the latter educational course. However, the literature regarding non-contact interventions is most limited by a lack of information about the training/educational courses implemented, making firm conclusions about the discrepancy in findings problematic, and questioning whether such interventions could be replicated.

Taken together, the evidence is not robust enough to recommend particular interventions to change perceptions of adults with ID over others, in contrast to previous reviews highlighting the importance of positive contact and educational interventions. This questions whether studies involving changing attitudes towards children with ID included in other reviews may account for these findings. At first glance, studies to change perceptions of children with ID highlight the effectiveness of contact interventions (e.g. Rillotta & Nettelbeck, 2007) and educational programmes (e.g.
Campbell, Gilmore & Cuskelly, 2003), so this possibility may be worthy of further consideration.

Methodological and design limitations

Along with limitations of individual studies and types of interventions, there are also design and methodological limitations common across the literature base. The samples used in studies were generally small and unrepresentative, questioning the generalisability of findings. Moreover, there were limited interventions conducted with the general public (4) and more conducted with healthcare professionals or students training to work in such professions (9). Although recent reviews highlight stigmatising attitudes towards PwID amongst healthcare professionals (Pelleboer-Gunnink, Van Oorsouw, Van Weeghel & Embregts, 2017), it seems the problems more widely reported for PwID relate to perceptions of the general public, including social exclusion and discrimination (Verdonschot et al 2009; Home Office, 2016). This also links to a theme throughout the review around interventions making already positive attitudes even more positive as noted in four studies (Nosse & Gavin, 1991; Walker & Scior, 2013; Shields & Taylor, 2014; Jones et al, 2015), and potentially more when considering studies not providing baseline data (Laking, 1988; Hall & Minnes, 1999; Varughese & Luty, 2010; Varughese et al, 2011). Hence, it appears necessary for interventions to target appropriate people or groups and for studies to establish their attitudes are initially negative, rather than working on attitudes unlikely to cause the societal problems PwID experience, or working on the reformed.

Additionally, there is a dearth of qualitative studies, with only one study identified using a formal qualitative analysis, and the other three qualitative studies lacking rigour and transparency meaning their findings could not be relied upon. Although quantitative
studies can suggest if attitude change occurs according to measurement of predefined variables, this does not allow participants to express their experience of an intervention in an undetermined way (Willig, 2013). Thus, qualitative research may provide a richness and texture to participants’ experiences of interventions that quantitative studies do not provide.

Of the quantitative studies, there are limitations around measurement of attitude change. Firstly, all of the measures are self-report, susceptible to social desirability effects (van de Mortel 2008). Secondly, there is no common instrument used, with some authors opting for idiosyncratic measures and others using a variety of standardised measures. The lack of a valid and reliable measure of attitude change in ID research is reported elsewhere (Werner, Corrigan, Ditchman & Sokol, 2011), and the problems with this are reflected in the review, as making comparisons across studies is difficult. Thirdly, only two studies report follow-up measures, and this is only after four weeks (McConkey et al, 1983; Walker & Scior, 2013). Hence, the long-term effectiveness of interventions to change attitudes is questionable. Fourthly, the instruments do not explicitly measure attitude change relative to theoretical constructs. For example, the tripartite model of attitudes suggests attitudes are comprised of emotional, behavioural and cognitive components (Breckler, 1984). Studies generally appear to measure the cognitive and emotional components, with only two studies measuring behavioural change (Hall & Minnes, 1999; Walker & Scior, 2013). With recent research suggesting self-reported attitudes towards PwID are improving (e.g. Ouellette-Kuntz et al, 2009), behaviour towards PwID within society is more problematic including social exclusion (Verdonschot et al, 2009) and discriminatory abuse (Home Office, 2016), Thus, whether attitude change translates into meaningful behavioural change appears a more important focus. To summarise, there are multiple problems with measurements of perception
change used, culminating in the lack of a standardised, theoretically based measure in the ID literature.

Moreover, none of the studies identified asked PwID themselves whether peoples’ perceptions or behaviour towards them has changed following interventions. Qualitative research has shown PwID are aware of the stigmatised attitudes of others (Jahoda & Markova, 2004), and therefore, could be potential informants on whether attitudes are changing. Ali, Strydom, Hassiotis, Williams and King (2008) designed a 10-item measure of perceived stigma in PwID, but this is yet to be used across intervention studies. Offering the perspective of PwID on attitude change may be enlightening, and it appears the literature base needs to be updated to align with the modern understanding of the importance and value of having PwID involved in research (Tarleton & Ward, 2005). Similarly, no studies use family members of PwID as informants, noted within reviews elsewhere (Werner et al, 2011). Families are shown to be aware of how negative perceptions impact upon the lives of their loved ones (Aiden & McCarthy, 2014), so they could also be helpful informants within research around the effectiveness of interventions.

Furthermore, there is limited information regarding the nature of interventions, questioning whether they are replicable. Similarly to the drawbacks around measures, there is limited theoretical literature drawn on in designing or describing interventions. For example, the contact interventions do not explicitly outline how the intervention maps onto the four efficacious components outlined in Allport’s (1954) contact theory, if at all. There is also limited information around whether interventions are attempting to change attitudes towards people with more mild or severe ID. It is reported people with mild ID are less stigmatised, and people want more social distance from those with
more severe ID (Oullelette-Kuntz et al, 2010). Hence, this differentiation appears important, and would help clarify if interventions are more effective at changing attitudes towards different severities of ID. In summary, more clarity around what interventions entail and their aims would benefit the literature greatly.

**Implications and future research**

Due to the design and methodological limitations emphasised, there is no consensus around which interventions are most effective to change perceptions of adults with ID, so the recommendations for those implementing interventions are limited. To bring the literature closer to making such recommendations, the evidence base would benefit more broadly from intervention studies that:

- Clearly outline the nature of interventions, drawing on relevant theoretical constructs and provide enough information for replication
- Clarify the severity of ID the intervention seeks to change attitudes towards, to illuminate discrepancies in intervention efficacy for different severities of ID
- Use follow-up measures to determine if effects are maintained over time

Specifically for quantitative research, the literature would benefit from intervention studies that:

- Focus on changing negative attitudes through interventions, rather than making positive attitudes more positive
- Implement randomised controlled trials, using repeated measures designs and random allocation to intervention
- Recruit large, representative samples with clarity around sampling procedures
• Use standardised rather than idiosyncratic measures of perception change that are valid, reliable and sensitive

• Use multiple measures to assess attitude change, considering the tripartite model (Breckler, 1984), and particularly tapping into whether the intervention produces behavioural change

• Use measures to assess whether PwID think people’s attitudes have changed towards them, for example, Ali et al.’s (2008) measure of perceived stigma in PwID, and consider families as informants in intervention research

Studies into indirect contact interventions incorporating the above elements would also be beneficial, with the promising results of interventions thus far, and the possibility of implementing such interventions on a large scale in a short time. Moreover, developing a gold-standard tool that measures the multiple facets of attitude change, with versions for target populations and PwID may bring standardisation across the literature, and allow comparison across intervention studies.

Specifically for qualitative research, the literature would benefit from:

• A surge of studies using qualitative methodologies, due to the dearth of literature

• Good quality research, using formal qualitative analysis to ensure rigour and limit bias, and with transparency around the author’s viewpoint

• Studies considering the experiences of PwID and their families in establishing whether attitudes change towards them following interventions

Finally, a systematic review specifically around changing attitudes to children with ID may shed light on why the recommendations from previous reviews have not been substantiated here.
Limitations of the review

Limitations of this review include only using studies produced in the English language, potentially excluding reports of the effectiveness of interventions written in other languages. This may be a source of publication bias, accompanied by only using original articles from peer-reviewed journals. Although applied to ensure evidence quality, this may omit potentially illuminating research. Relatedly, there may also be interventions conducted to change attitudes towards PwID informally, but this review does not include anecdotal evidence from such interventions. Additionally, the review only incorporates ‘named and claimed’ intervention studies, so evidence from projects not specifically designed to change perceptions but having these knock-on effects are not included. However, identifying such studies may be problematic. Finally, authors were not contacted to request further information regarding their interventions, so critique around limited information regarding this may not be fully substantiated, and relate more to word count limitations within journals.

Conclusion

This review establishes similar findings to related research highlighting the difficulties around drawing firm conclusions regarding the effectiveness of interventions to change perceptions of PwID, due to a dearth of high-quality studies. What this research adds, or takes away from the existing reviews is evidence has not been found to favour one intervention type over others. Nonetheless, the review contributes clear guidelines around future research to improve the evidence base, and also illuminates the exclusion of the views of PwID in attitude change research, not identified elsewhere. Addressing these limitations may bring the literature closer to answering the question of which interventions are effective to change perceptions and for whom, to ultimately improve the lives of PwID.
References


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Part two: Empirical Paper
Changes in understandings and perceptions of individuals, significant others and community members involved in a theatre company for people with intellectual disabilities.

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This paper is written in the format ready for submission to the *Journal of Community Psychology* (see Appendix 6 for submission guidelines).

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Abstract

Aims: Theatre companies to show more positive capabilities and identities of people with intellectual disabilities (ID) have been established. Existing research focuses upon sole theatre performances, and rarely includes the impacts on those in the immediate or wider contexts of people with ID.

Methods: The impacts of a theatre company on understandings and perceptions of ID from multiple perspectives were explored. Interviews with members with ID, and focus groups with significant people in their lives and community members were conducted, and analysed using thematic analysis.

Results: Four superordinate and nine subordinate themes were identified. The theatre company increased members’ connectivity, allowed them to experience normality, and enabled growth for all participants, leading to a desire to extend the theatre company’s ethos elsewhere.

Conclusions: The value of the theatre company is emphasised, with broader implications for developing and funding similar organisations.

Key words: Intellectual disabilities; perceptions; arts; theatre; community psychology
Introduction

People with intellectual disabilities (PwID) have long been marginalised within society, perceived as inferior to those without a disability (While & Clark, 2009). Whilst some sources suggest society’s perceptions of PwID are improving (e.g. Ouellette-Kuntz, Burge, Brown & Arsenault, 2009), others highlight the bullying and hostility PwID face (Scior & Werner, 2015), and their widespread exclusion from various aspects of ‘normal’ life including employment and social relationships (Chappell, 1998; Scior, 2003; Flynn & Russell, 2005; Scior & Werner, 2015). Furthermore, Mencap’s (2016) recent campaign highlights the substantial misunderstandings about intellectual disabilities (ID) amongst the public, such as ID being mental illnesses, and also illuminates society’s desire to maintain their distance from PwID. Thus, societal perceptions and understandings of PwID appear dominated by negativity and confusion.

This negativity is not just limited to wider society. Lewis and Stenfert-Kroese (2010) found nursing staff saw working with PwID as undesirable, regarding them as difficult, uncooperative and aggressive. Moreover, other healthcare staff are shown to distance themselves from PwID, to view and treat them as the same, and to focus upon controlling their behaviour, rather than engaging them in therapeutic conversations (Kordoutis, Kolaitis, Perakis, Papanikolopoulou & Tsiantis, 1995). Additionally, research exploring the perceptions of family members of PwID highlight how parents experience difficult feelings due to losing a ‘perfect child’ in fantasy, and can become overprotective as they feel somehow to blame for their child’s disability (Chandramuki, Shastry & Vranda, 2012). Parents are also shown to express concerns about their children’s independence, employability and opportunity for family life in the future (Heiman, 2002). Hence, negative perceptions and expectations also appear prevalent in the immediate contexts of PwID.
These negative perceptions in immediate and wider contexts are thought to create a self-fulfilling prophecy for PwID. Thus, they internalise the expectations of others (Scior, 2003), and experience low self-esteem, worth and confidence, resulting from feeling rejected, devalued and insignificant (Shessel & Reiff, 1999; Goodley, 2001). This can also negatively impact upon the emotional wellbeing of PwID, with depression, anxiety, anger, and shame prevalent, following striving for acceptance and status in communities that are stigmatising and isolating (Shessel & Reiff, 1999; Jahoda, Wilson, Stalker & Cairney, 2010).

The ideas presented thus far can be conceptualised in terms of Bronfenbrenner’s (1979) Ecological Systems Theory, describing five different levels of a system individuals interact with. Hence, negative perceptions of PwID infiltrate numerous layers of context starting with their immediate context or ‘microsystem’, including family and staff perceptions, to the highest level of context or ‘macrosystem’, in that the wider public perceptions of PwID are largely negative. This then appears to pervade the core of the model, with PwID internalising low expectations of others.

Previously, the contextual factors contributing to the poor emotional wellbeing of PwID were not recognised. Hence, approaches to working with PwID arose from the medical model, focusing on ‘fixing’ the person with ID as they were perceived as ‘the problem’ (Schalock et al, 1994) i.e. working at the lowest level of Bronfenbrenner’s (1979) model. However, the social model of disability (Schalock et al, 1994) posited a new approach, highlighting the problematic relations between PwID and wider society as the fertile ground for change, rather than an individual fix (Ramcharan & Grant, 2001; Dudley-Marling, 2004) i.e. extending to wider levels of Bronfenbrenner’s (1979) model. Thus, interventions emerged involving integrating PwID within society to
address these problematic relations including unified sports (Ozer et al, 2011; Sullivan & Glidden, 2014) and adventure activities (Anderson, Schleien, McAvoy, Lais & Seligmann, 1997), and programmes to promote friendships amongst people with and without ID (Hardman & Clark, 2006). Moreover, interventions to challenge negative perceptions of PwID that may contribute to these problematic relations initially were implemented, including educational programmes involving face-to-face contact with PwID (e.g. Bailey, Barr & Bunting, 2001) and indirect contact through media portrayal (e.g. Walker & Scior, 2013). Furthermore, interventions involving significant people in PwID’ lives emerged including interventions to change staff perceptions (e.g. Tsiantis, Diareme & Kolaitis, 2000) and family programmes allowing open discussions regarding their concerns (Hornby, 1992). These later approaches involving stakeholders in higher levels of context are consistent with Transformative Community Organising models, suggesting meaningful social change requires working at individual, collective and societal levels (Wernick, Kulick & Woodford, 2014).

Disability arts have also been used to improve relations between people with disabilities and society (Cameron, 2007). Arts projects are consistent with Capability Theory suggesting we focus on what people with disabilities cannot do, rather than what they can do (Goodley, 2001; Vorhaus, 2015) and Community Development Theory, suggesting participation is key in challenging disempowerment (Sloman, 2011). Thus, arts projects provide an opportunity for people with disabilities to show their otherwise hidden abilities and be an active participant, respectively. Matarasso (1997) highlighted multiple benefits the arts can have for individuals in marginalised groups including personal growth, developing social bonds and improved wellbeing. On broader levels, arts are shown to strengthen community cohesion and have transformative power
through improving perceptions of marginalised groups and bringing about social change (Matarasso, 1997; Thornton, 2010; Hodges, Fenge & Cutts, 2014).

For PwID specifically, disability arts appear a fitting ‘solution’ for the difficulties outlined thus far, if involvement can improve wellbeing and change societal perceptions. Thus, projects for PwID have emerged including art, multimedia and drama groups showing similar, positive impacts to projects with other marginalised people (Matarasso, 1997). Numerous theatre companies have also been established, with theatre specifically offering an opportunity to challenge perceptions and show more positive possibilities, capabilities and identities of PwID (Cameron, 2007; Roulstone, 2010; Vorhaus, 2015). PwID report benefits of being involved in such theatre companies including improved self-confidence and self-identity (Hall, 2011). Additionally, PwID have noted how performances increase their visibility within society and challenge negative perceptions (Goodley & Runswick-Cole, 2011).

However, linking back to Transformative Community Organising models, meaningful change is thought to require intervention beyond individuals to higher levels of context (Wernick et al, 2014), and thus, expanding outwards to conceptualise in terms of Bronfenbrenner’s (1979) model. Limited research has considered the impact of theatre on families of PwID or on wider society, but the small literature base that exists suggests both groups are surprised by what PwID can do (Hargrave, 2010; Vorhaus, 2015). The need for more research considering the impacts of theatre on stakeholders in wider levels of context is frequently highlighted (e.g. Faigin & Stein, 2010). Furthermore, the literature base as a whole tends to consider the impacts of one theatre performance at a specific time e.g. Hargrave (2010), rather than any broader changes or perceptual shifts over a prolonged period.
Therefore, the specific gap in the literature appears to be considering the impacts of a theatre company for PwID for stakeholders in various levels of context, going beyond the impacts of one performance at a specific time. Although there is more research considering the impacts of theatre on PwID themselves, this is still limited by focusing only on specific performances. Thus, a study combining these elements, that is, the impact of a long-running theatre company on PwID themselves, and also those in their wider contexts is yet to be conducted. If this gap in the literature was addressed, this may suggest alternative approaches to changing perceptions of PwID amongst those close to them and in wider society. In turn, if such perceptions negatively impact upon the emotional wellbeing of PwID and their view of themselves, this may also suggest alternative ways to improve the wellbeing of PwID and generate more positive self-identities.

**Research Questions**

The study considered changes in understandings and perceptions around ID following involvement in an established theatre company from various levels of context including PwID themselves, those in their immediate context, termed ‘significant others’ and those from the wider community. The following research questions were proposed:

- How do PwID, significant others and community members make sense of their involvement in a theatre company?
- How does this involvement impact upon how PwID understand and perceive themselves, how they think others understand and perceive them, and on how they live their lives?
• How does this involvement impact upon the understandings and perceptions of PwID amongst significant others and community members, and on how they live their lives?

As the research was interested in peoples’ experiences of being involved with the theatre company, a qualitative approach was adopted. Particularly, thematic analysis can be used to highlight variations in conceptualisations of phenomenon across groups (Joffe, 2012), so this is consistent with research involving multiple populations.

Method

Design
A qualitative design using semi-structured interviews with members of the theatre company who have ID, and focus groups with significant others (SO) and community members (CM) was employed to explore the impacts of the theatre company and perception change around ID from multiple perspectives.

Recruitment
Participants were recruited through a theatre company for PwID in Yorkshire. The organisation has approximately 150 members with ID and other varying needs. The theatre company offers various workshops run by professional artists including; the teaching and practising of stage techniques culminating in a theatre production annually, dancing, singing, playing musical instruments, film-making, and media publishing skills. Alongside improving members’ theatrical and musical skills, the company also promotes its secondary benefits including increasing the employability, physical fitness, and creativity of its members, and providing the opportunity for social
development, independence and team-working skills. The company also organise regular events to showcase their work to key stakeholders, and the wider community.

Three groups of participants were recruited through the theatre company; Members of the company who have ID, SO in members’ lives, and CM. Participants were recruited through flyers (Appendices 8-9) placed around the company building, given to potential participants at events by a company co-director, and e-mailed to the mailing list and potential participants. The co-director gave contact details of interested participants to the researcher to follow-up, or they contacted the researcher directly.

1. Theatre members (TM)

*Inclusion Criteria*

Members of theatre company were eligible to participate if they:

- Were over the age of 18.
- Had an intellectual disability. This was not screened, as the theatre company is for PwID. Participants were included if they had additional needs such as Autism Spectrum Conditions or a physical disability, as this was thought to add to the richness and authenticity of the data.
- Expressed an interest in sharing their views about the theatre company.
- Were willing to sit with the researcher on a one-to-one basis.
- Were able to communicate verbally, due to collecting data via interviews.
- Were members of the theatre company for any length of time, to capture perspectives from varying levels of involvement.
- Had the capacity to consent to participate. This was assessed based upon the components of the Mental Capacity Act (Department of Health, 2005). Thus, it
was assumed individuals had capacity unless it was apparent they could not understand the research information, weigh up the pros and cons of participation, retain information about the research, or communicate a decision about participation.

Participants

The first author met with 23 TM to discuss the information sheet face-to-face, and spoke to one member via telephone (Appendices 10-11). One person could not participate, as they did not have an ID; they were identified as the one person who attended because they had a mental health problem. One person could not communicate verbally, three members decided they did not want to take part, and five people could not understand the research information so did not have capacity to consent. Overall, 14 members participated in individual interviews. 6-12 participants are recommended to achieve data saturation when using thematic analysis in small projects (Guest, Bunce & Johnson, 2006; Braun & Clarke, 2006), and so 14 participants exceeded this range.

TM provided demographic information prior to the interviews (Appendix 17), as detailed in Table 1. Slightly more male theatre members (n=8) participated than females (n=6), and all TM described themselves as White British. Ages ranged from 18-53 years (mean= 32.9 years), and participants lived in various settings including with family, supported housing, residential homes and independent living. Participants had been members for between six months and over nine years, and attended an average of four groups per week (range= 2-5).
### Table 1. TM’ demographics.

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Living arrangements</th>
<th>Length of time been a member</th>
<th>Number of times attend theatre company per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>TM1</td>
<td>26</td>
<td>F</td>
<td>White British (W/B)</td>
<td>Family home</td>
<td>9 years+</td>
<td>5</td>
</tr>
<tr>
<td>TM2</td>
<td>18</td>
<td>F</td>
<td>W/B</td>
<td>Family home</td>
<td>7-9 years</td>
<td>5</td>
</tr>
<tr>
<td>TM3</td>
<td>24</td>
<td>M</td>
<td>W/B</td>
<td>Family home</td>
<td>3-4 years</td>
<td>4</td>
</tr>
<tr>
<td>TM4</td>
<td>34</td>
<td>M</td>
<td>W/B</td>
<td>Residential home</td>
<td>9 years+</td>
<td>4</td>
</tr>
<tr>
<td>TM5</td>
<td>49</td>
<td>M</td>
<td>W/B</td>
<td>Supported housing</td>
<td>9 years+</td>
<td>2</td>
</tr>
<tr>
<td>TM6</td>
<td>50</td>
<td>M</td>
<td>W/B</td>
<td>Residential home</td>
<td>4-6 years</td>
<td>5</td>
</tr>
<tr>
<td>TM7</td>
<td>22</td>
<td>M</td>
<td>W/B</td>
<td>Family home</td>
<td>6 months-1 year</td>
<td>3</td>
</tr>
<tr>
<td>TM8</td>
<td>36</td>
<td>F</td>
<td>W/B</td>
<td>Supported housing</td>
<td>9 years+</td>
<td>5</td>
</tr>
<tr>
<td>TM9</td>
<td>25</td>
<td>M</td>
<td>W/B</td>
<td>Supporting housing</td>
<td>6 months-1 year</td>
<td>3</td>
</tr>
<tr>
<td>TM10</td>
<td>42</td>
<td>F</td>
<td>W/B</td>
<td>Supported housing</td>
<td>9 years+</td>
<td>4</td>
</tr>
<tr>
<td>TM11</td>
<td>30</td>
<td>F</td>
<td>W/B</td>
<td>Supported housing</td>
<td>6 months-1 year</td>
<td>4</td>
</tr>
<tr>
<td>TM12</td>
<td>24</td>
<td>M</td>
<td>W/B</td>
<td>Independent living</td>
<td>4-6 years</td>
<td>4</td>
</tr>
<tr>
<td>TM13</td>
<td>53</td>
<td>M</td>
<td>W/B</td>
<td>Residential home</td>
<td>9 years+</td>
<td>3</td>
</tr>
<tr>
<td>TM14</td>
<td>28</td>
<td>F</td>
<td>W/B</td>
<td>Supported housing</td>
<td>4-6 years</td>
<td>5</td>
</tr>
</tbody>
</table>

2. Significant others

**Inclusion criteria**

SO were eligible to participate if they expressed an interest in sharing their views about the theatre company, and were available when the focus groups were arranged. SO could be anyone with significant involvement in a member’s life, including family
members, carers and residential staff, and were included regardless of whether the person they cared about was involved in the interviews. SO were also included if they had become volunteers at the organisation, but there was a maximum of two volunteers per group to ensure their perspectives did not overwhelm the focus groups.

Participants

The first author contacted 23 significant people in members’ lives via telephone and e-mail regarding the research (Appendix 12). Seven people could not attend on the focus group dates, one person did not want to take part, one person could not take part on the day because the person they care for was distressed, and three people did not attend, in one case due to illness. This meant 11 significant others took part overall, six participants in the first focus group, and five in the second. The number of participants recommended to achieve data saturation and consider whether themes converge or diverge according to group using thematic analysis is 2-4 (Braun & Clarke, 2006), and is 4-8 to run focus groups generally (Wilkinson, 2008), so the focus group numbers fall within this 2-8 range.

SO provided demographic information prior to the interviews (Appendix 18), as detailed in Table 2. More female SO (n=7) participated than males (n=4). Ages ranged from 38-67 years (mean= 56.5 years), and all SO described themselves as White British, apart from one participant who did not specify their ethnic group. Six SO were parents, two were carers and three were support workers, and three participants were also volunteers. The amount of time their loved one had been a member varied from one year to over nine years (mean= 62.8 years).
Table 2. SO’ demographics.

<table>
<thead>
<tr>
<th>Participant number</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Relationship to member</th>
<th>Length of time loved one a member</th>
<th>Ways involved in the theatre company</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Focus group 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SO1</td>
<td>58</td>
<td>F</td>
<td>W/B</td>
<td>Parent</td>
<td>4-6 years</td>
<td>Mailing list, Donate, Attend performances</td>
</tr>
<tr>
<td>SO2</td>
<td>54</td>
<td>F</td>
<td>W/B</td>
<td>Parent</td>
<td>1-3 years</td>
<td>Volunteer</td>
</tr>
<tr>
<td>SO3</td>
<td>38</td>
<td>M</td>
<td>W/B</td>
<td>Support worker</td>
<td>3-4 years</td>
<td>Ex-volunteer</td>
</tr>
<tr>
<td>SO4</td>
<td>54</td>
<td>F</td>
<td>W/B</td>
<td>Support worker</td>
<td>9 years+</td>
<td>Mailing list, Donate, Attend performances</td>
</tr>
<tr>
<td>SO5</td>
<td>62</td>
<td>F</td>
<td>W/B</td>
<td>Support worker</td>
<td>9 years+</td>
<td>Attend performances</td>
</tr>
<tr>
<td>SO6</td>
<td>58</td>
<td>F</td>
<td>W/B</td>
<td>Parent</td>
<td>1-3 years</td>
<td>Mailing list, Attend performances</td>
</tr>
<tr>
<td><strong>Focus group 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SO7</td>
<td>56</td>
<td>M</td>
<td>W/B</td>
<td>Parent</td>
<td>9 years+</td>
<td>Mailing list, Donate, Attend performances</td>
</tr>
<tr>
<td>SO8</td>
<td>61</td>
<td>M</td>
<td>W/B</td>
<td>Parent</td>
<td>4-6 years</td>
<td>Mailing list, Volunteer, Attend performances</td>
</tr>
<tr>
<td>SO9</td>
<td>53</td>
<td>F</td>
<td>W/B</td>
<td>Parent</td>
<td>4-6 years</td>
<td>Mailing list, Donate, Attend performances</td>
</tr>
<tr>
<td>SO10</td>
<td>61</td>
<td>F</td>
<td>Not specified</td>
<td>Carer</td>
<td>9 years+</td>
<td>Mailing list, Donate, Attend performances</td>
</tr>
<tr>
<td>SO11</td>
<td>67</td>
<td>M</td>
<td>W/B</td>
<td>Carer</td>
<td>7-9 years</td>
<td>Attend performances</td>
</tr>
</tbody>
</table>
3. Community members

Inclusion criteria

Similarly, CM were eligible to participate if they expressed an interest in sharing their views about the theatre company, and were available when the focus groups were arranged. No specific inclusion criteria was placed on CM’ involvement, but some level of involvement was assumed due to them being known to the company. CM were also included if they had become volunteers at the organisation, but it was again ensured that their perspectives did not dominate the focus groups.

Participants

The first author contacted 11 CM via telephone and e-mail regarding the research (Appendix 13). One person could not attend on the focus group dates, leaving 10 CM participating overall, seven in the first focus group, and three in the second. This again fell within the 2-8 recommended range.

CM provided demographic information prior to the interviews (Appendix 19), as detailed in Table 3. More female CM (n=8) participated than males (n=2). Ages ranged from 30-83 years (mean= 62.8 years), and the majority of CM described themselves as White British, apart from one participant describing themselves as from another white background. CM had been involved with the theatre company from one year to over nine years. The nature of this involvement differed, but all CM identified attending company performances, with participants going to between 0-6 events per year.
Table 3. CM’ demographics.

<table>
<thead>
<tr>
<th>Participant number</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Ways involved in the theatre company</th>
<th>Length of time been involved</th>
<th>Number of theatre company events attended per year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus group 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CM1</td>
<td>63</td>
<td>F</td>
<td>W/B</td>
<td>Attend performances</td>
<td>9 years+</td>
<td>0-2</td>
</tr>
<tr>
<td>CM2</td>
<td>83</td>
<td>F</td>
<td>W/B</td>
<td>Mailing list Donate Attend performances</td>
<td>9 years+</td>
<td>3-4</td>
</tr>
<tr>
<td>CM3</td>
<td>34</td>
<td>F</td>
<td>W/B</td>
<td>Donate Attend performances</td>
<td>4-6 years</td>
<td>0-2</td>
</tr>
<tr>
<td>CM4</td>
<td>73</td>
<td>M</td>
<td>W/B</td>
<td>Mailing list Fundraiser Attend performances</td>
<td>4-6 years</td>
<td>3-4</td>
</tr>
<tr>
<td>CM5</td>
<td>73</td>
<td>F</td>
<td>W/B</td>
<td>Mailing list Volunteer Donate Attend performances</td>
<td>4-6 years</td>
<td>3-4</td>
</tr>
<tr>
<td>CM6</td>
<td>81</td>
<td>F</td>
<td>W/B</td>
<td>Donate Attend performances</td>
<td>7-9 years</td>
<td>5-6</td>
</tr>
<tr>
<td>CM7</td>
<td>63</td>
<td>M</td>
<td>W/B</td>
<td>Mailing list Attend performances</td>
<td>1-3 years</td>
<td>3-4</td>
</tr>
<tr>
<td>Focus group 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CM8</td>
<td>68</td>
<td>F</td>
<td>Other white background</td>
<td>Volunteer Attend performances</td>
<td>1-3 years</td>
<td>0-2</td>
</tr>
<tr>
<td>CM9</td>
<td>60</td>
<td>F</td>
<td>W/B</td>
<td>Attend performances</td>
<td>7-9 years</td>
<td>0-2</td>
</tr>
<tr>
<td>CM10</td>
<td>30</td>
<td>F</td>
<td>W/B</td>
<td>Attend performances</td>
<td>4-6 years</td>
<td>0-2</td>
</tr>
</tbody>
</table>
Procedure

Ethical approval was attained from the local University Research Ethics Committee (Appendix 7). Written consent was obtained from all participants prior to the interviews/focus groups (Appendices 14-16). Three theatre members could not read. Thus, an independent person was present whilst the researcher accurately read the consent form to the participant, and countersigned the form. Finally, participants were given contact details of relevant support services following participation (Appendices 24-25).

Data collection

Interviews and focus groups were guided by semi-structured interview schedules, using flexibly to allow participants to bring their own agendas (Smith, Flowers & Larkin, 2009). Participants were informed the researcher was interested in hearing about the impact of the theatre company on them, whether from the perspective of being a member, SO or CM. The schedules (Appendices 20-24) were developed based upon reviewing relevant literature, and discussions with PwID in designing the study regarding accessible language. All interviews and focus groups were conducted face-to-face, and were audio-recorded and transcribed. Interviews lasted between 11 and 60 minutes. The SO focus groups lasted 63 and 76 minutes, and the CM focus groups lasted 56 and 31 minutes.

Data analysis

A descriptive phenomenological epistemology underpinned the research, focusing upon participants’ experiences as they shared them (Appendix 27). Inductive thematic analysis was used to analyse the interviews and focus groups, as the research aimed to
identify patterns within data sets, and between groups (Braun & Clarke, 2006). The data sets were initially analysed separately, following Braun and Clarke’s (2006) guide:

1. Data was transcribed. The researcher read, re-read and noted points of interest across the transcripts.
2. Initial codes were produced. Appendix 26 provides a worked example of analysis.
3. Similarities amongst codes were searched for across each data set, considering how to collate the codes into broader themes and subthemes.
4. All of the coded extracts within each theme were re-read to see if they formed a pattern and validly reflected the whole data set. Reorganisations and movement between themes were made as necessary.

As there was similarity across the themes from the three data sets noted at this stage, the themes were integrated and considered as broader overarching themes across all groups. The final stage of analysis involved these themes being defined, named and storied, and considered contextually to the broader story of the data and relative to the other themes (Braun & Clarke, 2006). Idiosyncrasies to certain data sets were considered within themes, and whether the same theme materialised comparatively in different groups.

**Quality**

In designing the research, consultation groups were conducted at the theatre company to check the suitably of information sheets, consent forms and research procedures. During analysis, numerous measures were taken to ensure rigour and transparency associated with qualitative research (Elliott, Fischer & Rennie, 1999). Hence, the credibility and validity of codes was ensured by discussing codes with peer researchers in a qualitative research group, in research supervision, and through keeping a reflective diary to
monitor the researcher’s own perspectives and assumptions during the research process, a potential source of bias (Appendix 28). Furthermore, the results are presented using quotations, to show the link between the original transcripts and the consequent themes developed.

**Results**

Four superordinate and nine subordinate themes were identified across the data sets (Table 4). The analysis showed a differentiation between participants describing their own experiences of the theatre company and its impacts upon them, compared with discussing its impacts on the other participant groups. Therefore, where participants discuss their own experiences, not witnessed by other groups, this is presented separately. However, when other participants witness the same thing for that group, this is integrated. The participant group each theme/subtheme relates to (also see Table 4) and the presentation of the data is described throughout for clarity.

*Table 4. Overview of superordinate and subordinate themes. Brackets denote the participant group(s) each theme/subtheme relates to.*

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subordinate themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Connections (members)</td>
<td>1.1. Bonds with other members (members)</td>
</tr>
<tr>
<td></td>
<td>1.2. Community links (members)</td>
</tr>
<tr>
<td>2. A normal life (members)</td>
<td>3.1. Purpose and achievement (members)</td>
</tr>
<tr>
<td>3. People growing as people (all)</td>
<td>3.2. Self-relating (members)</td>
</tr>
<tr>
<td></td>
<td>3.3. Challenging perceptions of PwID (SO and CM)</td>
</tr>
<tr>
<td></td>
<td>3.4. Positive effect on wellbeing (members and SO)</td>
</tr>
<tr>
<td>4. A different direction (all)</td>
<td>4.1. Societal barriers for PwID (all)</td>
</tr>
<tr>
<td></td>
<td>4.2. What makes the theatre company successful (all)</td>
</tr>
<tr>
<td></td>
<td>4.3. Value of the theatre company (all)</td>
</tr>
</tbody>
</table>
1. Connections

Participants discussed the social and community links members made through the theatre company. The data is integrated, to reflect how the SO and CM discussed the connections members made, rather than this being their personal experience of greater connectivity.

1.1. Bonds with other members

Members discussed “making loads of new friends” (TM10) at the theatre company. They described not having a social life beyond the organisation, relating to difficult experiences with peers previously:

“I was a loner...because people kept calling me names” (TM2)

SO equally described their loved ones making friends, and this being their only social contact:

“if [daughter’s name] didn’t have to come here, she wouldn’t have any friends” (SO10)

Members also discussed romantic relationships with other members, and how this was going:

“the one I’ve had for a couple of months when I’m glad about” (TM14).
However, this was not a theme from the focus groups, suggesting romantic connectivity was only significant from members’ perspectives. Members also emphasised the importance of everyone having ID in developing social bonds:

“you’re surrounded by people you can relate to on some level whether it’s mental, emotional or even humane” (TM7)

SO also echoed the importance of members all having ID:

“that level of disability...or ability, it gives ’em a chance to talk about things that they’re maybe not comfortable talking to us about” (SO9)

SO provided an explanation for members interacting with each other easily, that members did not articulate:

“they don’t single people out like people without disabilities do” (SO6)

Members described their bonds going beyond friendship, describing the theatre company as a “second family” (TM4), appearing particularly poignant for members that were fostered. SO and CM also saw the bonds between members as like family:

“it’s just one big family” (SO5)

“they’re like a little family” (CM6)
Members discussed the importance of a helping aspect to their relationships with other members:

“I help people who aren’t as able as me” (TM1)

Furthermore, SO witnessed these helping relationships:

“I’ve really admired the way they respond to each other’s needs” (SO6)

CM could also relate to this from watching performances:

“they look after one another” (CM2)

Finally, members discussed a deeper understanding of relationships through their bonds with other members, being better able to deal with conflict:

“it’s just a case of standing back and...not getting involved...with other people’s problems...like I used to do” (TM6)

Moreover, SO described how experiencing relationships “brings another level of understanding” (SO1) for their loved ones.

1.2. Community links

Connectivity extended beyond the theatre company to members developing relationships with the wider community. Members described their experience of being known in the community:
“*I think it’s good…people get to know us*” (TM13)

SO also expressed how members being integrated within the community affected peoples’ behaviour:

“*they don’t get stared at or talked about*” (SO5)

CM discussed members’ connectivity with local society, and reflected on how this was not always the case:

“*they just accept that they’re part of the community, nobody questions it or, or makes a comment or anything…which is what it should have been like*” (CM6)

Additionally, members discussed people getting to know them from other areas, beyond the local community:

“*it’s just feels brilliant to know that people from all over the places…can come and watch*” (TM3)

SO also described their loved ones social connectivity extending beyond the local area, and how the theatre company helps in “*introducing them to a lot of new people*” (SO5).

2. *A normal life*

The theatre company was also thought to give members experiences of normality, where they are not treated as a person with a disability needing to be sheltered. Similarly, the data is integrated to reflect how SO and CM were witness to members
experiencing normality at the theatre company, rather than this being their personal experience.

Members discussed being challenged at the theatre company, describing the “complicated” (TM5) and “hard stuff” (TM1) they do, and wondering, “how am I meant to do that?” (TM2). Members also discussed aspects of the theatre company they dislike including “singing” (TM6), being “bored” (TM4) and “people winding you up” (TM1). However, one member articulated the importance of exposing PwID to adversity:

“don’t go to the point where you wrap ‘em up in a blanket and say it’s alright, nothing will hurt you ever ‘cos things will” (TM7)

Furthermore, members expressed an understanding of things they disliked including not always getting a main role; “everybody’s got to have their turn at doing something” (TM12) and the slow-pace of rehearsals; “I know you have to stop and start but just makes it perfect” (TM1).

SO also discussed the importance of their loved ones being “pushed to do things” (SO10):

“it’s not a bad thing you need rules in life don’t ya” (SO9)

SO described challenges in relationships experienced at the theatre company including “fallouts” (SO9), but how this is just “human nature” (SO7), emphasising the
normality of difficult experiences. Moreover, CM described seeing members challenged by facilitators, and their reaction to this:

“They don’t accept second best, that surprised me” (CM5)

Playing characters in performances appeared to enable members to be ‘normal’ and not have a disability, as articulated by one member:

“I was in my character and not myself” (TM11)

SO also saw the significance of being someone else for their loved ones:

“It’s really important that she gets that chance to understand that you can be something else” (SO1)

Being accepted at the theatre company also helped members feel ‘normal’ and changed their relationship with disability:

“We’re normal human beings like everybody else” (TM13)

SO also expressed the importance of acceptance in members feeling that their disabilities do not matter:

“Nobody has a disability they all have a ability…at a different level” (SO9).
3. People growing as people

Growing as people through involvement in the theatre company was relevant to all participants. However, the nature of this differed across groups, and there was a similar process around witnessing growth in others. Therefore, the participant group each subtheme relates to and how the data is presented is described throughout.

3.1. Purpose and achievement

The first subtheme is relevant only to members’ growth, but also witnessed by SO, so this is integrated. Members described gaining a sense of purpose through the theatre company, suggesting they would “be at a loose end” (TM6) without it, and it being “nice to know that you live to do something” (TM12). SO also described how their loved ones “wouldn’t be motivated” (SO5) without the theatre company. Additionally, having a purpose enabled members to achieve and identify their strengths. One member described conquering nervousness around performing:

“I absolutely pulled through it and I did absolutely brilliant” (TM11)

Achievement linked to pride for members, feeling “honoured” (TM3) when audiences enjoy the shows. Furthermore, SO expressed the importance of their loved ones achieving, and seeing them “blossoming” (SO11) over time.

3.2. Self-relating

Another aspect of members’ growth was finding and accepting themselves. This was unique to their perspective, and not witnessed by SO or CM, so only members’ data is presented within this subtheme. Members described their relationship with themselves
changing through involvement in the theatre company; “it’s seeing me in a new light” (TM1), and also their relationship with disability:

“I’m starting to accept what my dad always used to say, it’s what makes me unique from everyone else” (TM7).

Self-identity gained from the theatre company was also prevalent, particularly for one member not from the area:

“It makes me feel that I’m part of this... even though... I’m an adopted person but... it makes you feel at home” (TM13)

3.3. Changing perceptions of PwID

An aspect of growth relevant to SO and CM was their perceptions of PwID changing through the theatre company. Changes in SO’ perceptions were uniquely described by them and not witnessed by others, so their data is presented separately. However, changes in CM’ perceptions were described by them, but also witnessed by the other groups, so this is integrated.

SO expressed how their “perception of the people with disabilities changes, completely” (SO7) through the theatre company. One mother described her perceptions being challenged at performances:

“I was actually shamefully expecting a little bit of the awww factor but not at all” (SO6)
A father described the impact of his perceptions changing:

“it makes you er a lot more…understanding” (SO8)

CM also described their surprise at performances, and seeing members’ unexpected abilities:

“I had absolutely no idea what he was capable of until I’d seen him in that show” (CM3)

They also discussed the impact on their perceptions:

“it has changed my perception of them that I didn’t expect that they would be capable of putting on the performance that they are” (CM4)

Furthermore, CM described how ID “dun’t seem to bother them” (CM9) and the importance of seeing members cope:

“It’s really helped me and the community as well to have a respect and understanding” (CM8).

Members also discussed showing audiences their abilities, and the impact on the community:
“some people ... maybe think... ‘cos they’ve got a disability or a learning disability, they won’t be able to put on a show or anything and then when they come and see it, they think well they have” (TM8)

SO also described how the community are “blown away by what they see” (SO9).

3.4. Positive effect on wellbeing

The final aspect of growth relevant for members and SO was a positive impact upon wellbeing through the theatre company, manifesting in different ways. The data from each group is presented separately, but integrated where other groups witnessed the impacts upon their wellbeing.

Members described feeling “more happier” (TM4) since going to the theatre company. SO noticed this in their loved ones:

“he’s [son] just happier in himself”(SO2)

Members also discussed improved mental health, with one member describing how she was helped with eating difficulties by facilitators encouraging her to “eat snacks” (TM14), and another member no longer ringing emergency services because the theatre company gives her “something to focus on” (TM11). SO also witnessed improvements in their loved one’s mental health. One mother described how things might be different if her son was not a member:

“I truly believe [son’s name] would be on antidepressants” (SO2)
Members also described the theatre company increasing their confidence:

“It’s given me erm like confidence” (TM9)

SO noticed how their loved ones are more confident and “come out their shells” (SO10) at the theatre company. CM also saw members’ confidence increase, and thought this “must give more confidence all around” (CM5).

SO identified the positive effect of the theatre company upon their wellbeing, including making their “life easier” (SO2) and providing a respite function:

“that period when you know they’re...happy, I can breathe and I can just be me and that replenishes your energy to be with them again” (SO6)

The importance of seeing their children “learn and progress” was also discussed, and the impact of this on the wider family:

“it does ease everybody’s feeling of tension and stress” (SO1)

Overall, the theatre company appeared to give SO “one less thing to worry about” (SO9). CM also discussed the impact upon family wellbeing:

“to know that they’re safe and...they can enjoy what they’re doing, I think that must be a big benefit to mums and dads” (CM6)
4. **A different direction**

The final theme encompassed societal difficulties for PwID and how the theatre company offers something different. The groups articulated their own experiences of the subthemes, so data is presented separately throughout.

4.1. **Societal barriers for PwID**

Members discussed difficult experiences within society relative to having ID:

“I really, really hate when they when they in the wheelchair or they’ve got a disability or whatever and you with a carer or with your mum and dad or... grandma ...and they talk to them over that person...and I’m thinking yeah but I’m still here” (TM8)

Limited appropriate services for PwID were also a barrier:

“I did go to [day service name], yes it was good in the respect they could give me all the medication that I needed...but for me...needing stimulation for my brain to keep going, it wasn’t very good” (TM12)

SO articulated the negative perceptions held by society about their loved ones:

“when people, the general public think of people with learning difficulties, the perception starts low and you’ve got to build it up” (SO1)

SO also described limited appropriate services for PwID, and how the theatre company was unique:
“there’s nothing around here like this” (SO3)

CM discussed negative perceptions of PwID from a historical perspective:

“they were never given a chance at all” (CM1)

They were the only participants expressing hope that perceptions of PwID were improving, referring to the Paralympics (CM7) and children with ID being on television (CM5).

4.2. What makes the theatre company successful

Participants discussed the theatre company’s success, comparative to the negative perceptions of PwID, and inappropriate services elsewhere. Members appeared less aware of what made the organisation successful generally, but stated what made it successful for them personally, including things always being “done at your own pace” (TM7), and the co-directors being “a major support” (TM12).

For SO, focusing on members’ strengths appeared poignant in making the theatre company successful:

“I think they focus on the ability and forget the dis” (SO6)

SO also described members being consulted on decisions:

“he [son] said it’s good because you can come in and it’s not like school, it’s not like college, you’re told right that you’ve gotta get that done, they’re asked” (SO2)
SO also emphasised the value of the facilitators, through “putting some vision there” (SO11) for members. They described them going the extra mile, and individualising activities to member’s needs:

“They’re looking at what other things people want to do, it’s not all about just being stood on a stage” (SO4)

CM also discussed the importance of the facilitators, including the “communication” and “organisation” they offer (CM8). However, the theatre company’s location appeared most prevalent to its success from the community’s perspective, including being in a “musical town” (CM8), and being “properly ground roots, local people...rather than somebody saying we’ve got loads of funding and saying we’re gonna start this erm theatre group” (CM3).

4.3. Value of the theatre company

In the context of the societal barriers for PwID and the theatre company offering something different, participants discussed how much they valued the theatre company and wanted to extend its ethos elsewhere. Members discussed how the theatre company took priority over other activities:

“I’ll cancel my Friday, I’d rather be here” (TM6)

Members also expressed how going to the theatre company was the “best thing” (TM13) they had done, and its value for them:
“I thought there was a puzzle missing from my brain you know like a piece of jigsaw missing...Like mmm what's missing? And yeah this was missing” (TM2)

Members discussed starting similar companies in different places, and a desire to “have organisations all round the country” (TM3).

SO also spoke about the theatre company positively, including it being “fantastic” and “amazing” (SO3), and expressed its value in their life:

“if [theatre company name] weren’t here anymore and it makes me feel a little bit sad” (SO3)

This perceived value meant some SO had volunteered at the theatre company, and others were considering this for their retirement:

“I’ve been thinking about when I finish work...could I do something to help them” (SO7)

SO discussed increasing awareness of the existing organisation and improving transport links, rather than making new organisations as members described. They thought it “would certainly improve other peoples’ perceptions...if they were out there more” (SO7). There was an undertone of frustration the company was not widely known about already:

“I don’t think they get out there in the mainstream world enough to promote what they do” (SO9)
CM also spoke positively about the theatre company, expressing how “they are quite special” (CM4). This also led a participant’s son to volunteer:

“he loved volunteering didn’t he and he got a lot out of it” (CM10)

CM also spoke about the possible impact of extending the ethos of the theatre company elsewhere:

“it’d help people bond more” (CM1)

Discussion

Overview of findings
This qualitative study explored the impact of an established theatre company at various levels of context, including on members with ID, significant people in their lives and the wider community. The specific objectives were to understand how people made sense of their involvement in the theatre company, how this impacted upon their understandings and perceptions of ID, and whether it impacted upon their lives. The analysis identified an important process around participants bearing witness to change in other groups. Hence, two superordinate themes relating to impacts upon members noticed by themselves and the other groups emerged, namely making social and community ‘connections’, and living ‘a normal life’ through the theatre company. Two further superordinate themes related to all participants, involving ‘growing as people’ and the theatre company offering ‘a different direction’, but the meaning of these themes varied across groups. The themes will now be contextualised relative to
empirical and theoretical literature, with consideration to relationships between themes and implications for practice.

The theatre company impacted on members’ lives through them developing social connections and deeper understandings of relationships. It seemed members only had friends through the theatre company, which is consistent with literature highlighting widespread exclusion of PwID (Scior & Werner, 2015) and society’s desire to maintain their distance (Mencap, 2016). The importance of all members having ID in developing bonds was proposed, consistent with research from other theatre companies noting that when people with disabilities come together, they realise shared experiences and develop solidarity (Cameron, 2007; Calvert, 2009). Additionally, this fits with social psychology theories suggesting similarity forms the basis for social bonds (Codol, 1984). The helping aspect to members’ relationships also appeared key, and contrasts with the dependent role in which PwID are usually placed, needing help themselves rather than being able to help others (Flynn & Russell, 2005; Goward & Gething, 2005). Developing community links also contradicts the usual picture of PwID as isolated and invisible (Jahoda et al, 2010). Thus, developing social and community connections through the theatre company appears to promote new understandings of ID for members, SO and CM, in seeing PwID as integrated, social beings that can take helping roles.

Developing romantic bonds was another way the theatre company impacted upon members’ lives, consistent with research suggesting PwID seek romantic relationships, despite not usually having this opportunity (Scior, 2003). However, this only came from the interviews, suggesting members’ understandings and perceptions of themselves may have changed to include a romantic identity, but this was not seen from
the perspectives of SO or CM. Harflett and Turner’s (2016) review highlights how PwID face numerous barriers to developing romantic relationships including the attitudes of their loved ones and society. Thus, despite engaging in romantic relationships, the theatre company was not shown to change these perceptions of SO or CM to include romantic identities of PwID.

A new understanding of ID that also emerged was that PwID can lead a ‘normal’ life if they are enabled to. Research suggests PwID are usually sheltered from normality because they are seen as vulnerable people who need protecting (Flynn & Russell, 2005; Goward & Gething, 2005). However, members were shown to experience challenges positively, and SO also recognised the importance of this. This suggests the theatre company enabled a new understanding of PwID for themselves and others that encompassed being able to cope with adversity, just as in ‘normal’ life. Playing a character also facilitated members being seen as ‘normal’, supported by previous literature showing that theatre enables actors to be someone else and activates alternative, capable identities of PwID (Hargrave, 2010; Trowsdale & Hayhow, 2013). Thus, being a character appears to promote a new understanding of PwID that does not define them as disabled, and instead, sees them as equivalent, ‘normal’ human beings (Gjaerum & Rasmussen, 2010).

A third theme incorporated participants growing as people through the theatre company. Having a purpose and achieving appeared an important element of growth for members, consistent with theories of wellbeing highlighting these as important components in psychological wellness (e.g. Maslow, 1943). Furthermore, developing confidence was another way the theatre company impacted members’ lives, a benefit noted from other theatre companies for PwID (e.g. Hall, 2010). Members also identified gaining more
positive self-identities and self-acceptance through the theatre company, also highlighted in previous theatre studies (e.g. Hall, 2010). However, different ways of self-relating were only noticed from members’ perspectives, and perhaps relates to family members’ difficulties acknowledging their loved ones struggle with being ‘disabled’ because they feel somehow to blame (Chandramuki et al., 2012).

Additionally, growth for members encompassed improved wellbeing through the theatre company, also highlighted in other arts (Matarasso, 1997) and theatre projects (Faigin & Stein, 2010). However, the improvement in wellbeing of SO is not highlighted in the literature elsewhere, and this new finding may relate to the theatre company providing a respite function, with breaks in caring linked to improved wellbeing amongst caregivers (Mencap, 2012).

Furthermore, the theatre company changed SO and CM perceptions of PwID. Other theatre studies similarly highlight how actors’ capabilities surprise people and change their expectations (Gjaerum & Rasmussen, 2010), and how theatre can rewrite identities of PwID (Calvert, 2009). However, this appeared to go deeper for participants in this study, making them more understanding and respectful of PwID. This suggests possible ways of changing perceptions of PwID, which previous reviews have struggled to establish (Seewooruttun & Scior, 2014). Notably, others did not witness the change in perceptions of PwID for SO. This may indicate that people do not expect families and caregivers to hold negative perceptions of their loved ones, but this study and previous literature (Heiman, 2002; Lewis & Stenhert-Kroese, 2010) highlights how this can be a challenge for those in the immediate contexts of PwID, with implications for supporting families and caregivers.
The final theme encompassed the ‘different direction’ the theatre company offered. A backdrop of negative societal perceptions of PwID, coupled with limited appropriate services highlighted to participants what is different about the theatre company and what makes it successful. Thus, the ethos, location and support offered appear valued aspects to its success, consistent with literature around other theatre projects (Hall, 2010). Furthermore, these successful components appear to provide PwID with the opposite of what research suggests are their usual experiences. For example, the theatre company gives them choice rather than choices being made for them (Conroy, 2009), activities are individualised to their needs rather than being seen as a homogeneous group who are treated indistinguishably (Kordoutis et al, 1995), and the organisation focuses on their strengths, rather than seeing them from a ‘deficit’ model (Goodley, 2001; Vorhaus, 2015). This appears to promote new understandings and perceptions that involve PwID making decisions, being individuals and possessing strengths. Furthermore, it seems seeing an organisation take ‘a different direction’ has inspired participants to see what could be established for PwID in other places to have similar, positive impacts.

Additionally, participants described the theatre company being like a family. Although this fits with the ‘connections’ members made, the characteristics of the theatre company and peoples’ experiences may fit with family theories more broadly. Research suggests characteristics of families working well incorporate experiencing positive emotions, supporting each other, being part of the wider community and dealing with disagreements and difficulties effectively (Stratton, Bland, Janes & Lask, 2010). Thus, the characteristics of the theatre company and the experiences members, SO and CM report are consistent with components of ‘functional’ families more broadly.
Although the themes are presented separately, they may also be interrelated. The theatre company was shown to improve members’ psychological wellbeing, as encompassed within the ‘people growing as people’ theme. There are numerous factors from other themes that research suggests relate to psychological wellness generally including; having social relationships, helping others and being connected with wider society (Warin, 2013) as outlined in the ‘connections’ theme; and overcoming adversity and being accepted (Warin, 2013) as stated in the ‘a normal life’ theme.

Moreover, there are factors associated with PwID’ wellbeing more specifically which the theatre company impacts upon. Thus, negative perceptions and expectations of those in the immediate and wider contexts are shown to negatively impact upon the emotional wellbeing of PwID (Shessel & Reiff, 1999), and so improvement in the perceptions of SO and CM as reported in the ‘people growing as people’ subtheme may also contribute to the improved wellbeing of PwID. For SO specifically, poor emotional wellbeing of caregivers can impact upon those they care for (Mencap, 2012), so the improved wellbeing of SO also reported in the ‘people growing as people’ subtheme may also have a reciprocal relationship with improvements in members’ psychological wellbeing. Finally, if SO and CM have new understandings and perceptions of PwID as reported in the growth subtheme, this may impact upon PwID seeing themselves differently (‘self-relating’ subtheme), as research suggests PwID internalise the negative perceptions and expectations of others (Scior, 2003). In turn, this may improve the wellbeing of members, as research suggests self-acceptance is linked to psychological wellness (Warin, 2013). Hence, the themes presented may be interrelated and cyclical, and considering the themes together may illuminate the relationship to the final theme; participants value the theatre company and want others to take ‘a different direction’, because of the positive impacts outlined within the other three themes.
Limitations

The majority of participants were ‘White British’. Research identifies different cultural conceptualisations of ID (e.g. Fatimilehin & Nardirshaw, 1994) meaning it is unclear whether the changes in understandings and perceptions of ID outlined would be found cross-culturally. Additionally, participants volunteered to participate, which may open the study to self-selection bias, and potentially favour the research towards positive perspectives of the theatre company (Rutherford, 2014). Finally, the CM were recruited through the theatre company and known to the organisation in some capacity. Thus, the focus groups may not have represented the views of CM without any affiliation to the theatre company.

Using focus groups to collect data may also have limitations. Although the researcher facilitated the groups to hear everyone’s perspective, some participants made more contributions, and therefore, their perspectives may be more represented in the study findings (Stewart & Shamdasani, 2014). Furthermore, social desirability can affect the validity of focus groups (Stewart & Shamdasani, 2014), but the effect of this appears minimal, as participants shared negative perceptions of PwID.

Finally, qualitative analysis allows the researcher to explore the perspectives of those involved in the research, but does not suggest generalisability to others (Willig, 2013). Therefore, other members, SO or CM may have different, but equally valid experiences that the research does not capture. Moreover, although an interpretative approach was not adopted, the researcher brought their own beliefs, assumptions and approach, suggesting another researcher with a different theoretical stance or set of personal experiences may have made a different contribution to the data. Therefore, the
researcher is open about such beliefs and assumptions (Appendices 27-28) to maintain transparency (Elliott et al, 1999).

*Implications*

The analysis revealed an important process around participants bearing witness to change in others. This process between PwID and SO is particularly relevant for practice, suggesting SO may be useful informants within services due to noticing changes in their loved ones, and provides further support for their inclusion (Worthington, Rooney & Hannan, 2013). Additionally, perception change amongst SO was not recognised by other groups, suggesting it may be unexpected that SO have negative perceptions of their loved ones, and therefore, do not receive support around the challenges associated with this. This study raises awareness of these possible negative perceptions, and the necessity of providing support. Furthermore, other groups did not bear witness to members developing romantic identities and becoming more self-accepting. Hence, this study further recognises the desire of PwID to engage in romantic relationships, and suggests those supporting PwID should acknowledge the importance of this. Moreover, a growing acceptance of themselves adds further evidence for PwID struggling with their identity and self-esteem relative to having ID, and implicates a potentially relevant factor to consider when working with PwID.

Additionally, this study outlines various benefits such organisations can have for PwID, SO and CM, and supports the development and funding of these services, particularly relative to government drivers to improve societal attitudes towards PwID (Parkin, 2016). To develop similar organisations for PwID, this study provides clear guidelines including companies that:
• Have strong facilitators who provide a vision for members and the organisation more broadly
• Offer practical and emotional support, rather than just activities
• Individualise activities to members
• Focus on strengths
• Consult members on decisions and facilitate choice
• Grow with the community

Finally, the findings may have implications beyond PwID. Thus, recent healthcare initiatives promote helping people develop purposeful lives within supportive communities to improve wellbeing (Mental Health Taskforce, 2016), which such organisations may facilitate. The findings also support Community Psychology approaches as an alternative to individual therapy, identifying successful ways of changing social relations and environments for marginalised groups to improve wellbeing (Kagan & Burton, 2005). They are also consistent with Transformative Community Organising models suggesting meaningful social change requires working at wider levels of context (Wernick et al, 2014). Thus, the implications may extend beyond PwID, to other oppressed, excluded and marginalised groups.

Future research
Future research may consider the impact of an established theatre company on community members unaffiliated with the organisation, recruited through local advertisement rather than the company itself, to see whether similar impacts are observed. Moreover, as this study did not show others’ understandings of PwID changed to include a romantic identity, future research to explore how this can be established is worthwhile, relative to the barriers PwID face in this area (Harflett &
Turner, 2016). Furthermore, research exploring the cost savings such organisations make to local services through improving wellbeing would also be influential, to promote the funding of such organisations within government budgets. Finally, research exploring the impacts of arts projects for other marginalised groups at multiple levels of context would be valuable, to discover whether the benefits reported are more broadly applicable than to PwID.

Conclusion
This study highlights the changes in understandings and perceptions of ID bought through involvement in an established theatre company for PwID themselves, significant people in their lives and the wider community. These changes include seeing PwID as sociable, happy, ‘normal’ individuals who can make decisions, help others, and possess various strengths. The theatre company was also shown to improve the wellbeing of members and significant people in their lives. These findings have implications for something participants articulated themselves; that similar organisations should be established elsewhere and for other marginalised groups, to enable others to experience the multitude of benefits outlined.
References


Part three: Appendices

1. GENERAL
The Journal of Applied Research in Intellectual Disabilities is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. 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. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit http://authorservices.wiley.com/bauthor/ for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

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Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements
Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship. It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

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Clinical trials should be reported using the CONSORT guidelines available at [www.consort-statement.org](http://www.consort-statement.org). A CONSORT checklist should also be included in the submission material ([www.consort-statement.org](http://www.consort-statement.org)).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: [www.clinicaltrials.org](http://www.clinicaltrials.org), [www.isrctn.org](http://www.isrctn.org). The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding
Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

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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:
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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'.

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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.

6. MANUSCRIPT FORMAT AND STRUCTURE

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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.

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- 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.

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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**

**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.

### 6.4 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](http://authorservices.wiley.com/bauthor/illustration.asp).


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View articles means that they do not yet have a volume, issue or page number, so Early View articles cannot be cited in the traditional way. They are therefore given a DOI (digital object identifier) which allows the article to be cited and tracked before it is allocated to an issue. After print publication, the DOI remains valid and can continue to be used to cite and access the article.

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#### Theoretical approach

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Study design

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Data collection

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<td>• Was the data collection and record keeping systematic?</td>
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Trustworthiness

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<th>5. Is the role of the researcher clearly</th>
<th>Clearly described</th>
<th>Comments:</th>
</tr>
</thead>
</table>
**described?**

For example:

- Has the relationship between the researcher and the participants been adequately considered?
- Does the paper describe how the research was explained and presented to the participants?

| Unclear | Not described |

| 6. *Is the context clearly described?*  |

For example:

- Are the characteristics of the participants and settings clearly defined?
- Were observations made in a sufficient variety of circumstances
- Was context bias considered

| Clear | Unclear | Not sure |

| 7. *Were the methods reliable?*  |

For example:

- Was data collected by more than 1 method?
- Is there justification for triangulation, or for not triangulating?
- Do the methods investigate what they claim to?

| Reliable | Unreliable | Not sure |

| Analysis |

<p>| 8. <em>Is the data analysis sufficiently</em> Rigorous | Comments: |</p>
<table>
<thead>
<tr>
<th><strong>rigorous?</strong></th>
<th>Not rigorous</th>
<th>Not sure/not reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>For example:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results?</td>
<td></td>
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<tr>
<td>• How systematic is the analysis, is the procedure reliable/dependable?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Is it clear how the themes and concepts were derived from the data?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>9. Is the data 'rich'?</strong></th>
<th>Rich</th>
<th>Poor</th>
<th>Not sure/not reported</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>For example:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• How well are the contexts of the data described?</td>
<td>Rich</td>
<td>Poor</td>
<td>Not sure/not reported</td>
<td></td>
</tr>
<tr>
<td>• Has the diversity of perspective and content been explored?</td>
<td></td>
<td></td>
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<tr>
<td>• How well has the detail and depth been demonstrated?</td>
<td></td>
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<tr>
<td>• Are responses compared and contrasted across groups/sites?</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>10. Is the analysis reliable?</strong></th>
<th>Reliable</th>
<th>Unreliable</th>
<th>Not sure/not reported</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>For example:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Did more than 1 researcher theme and code transcripts/data?</td>
<td>Reliable</td>
<td>Unreliable</td>
<td>Not sure/not reported</td>
<td></td>
</tr>
<tr>
<td>• If so, how were differences resolved?</td>
<td></td>
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<tr>
<td>• Did participants feed back on the transcripts/data if possible and relevant?</td>
<td></td>
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</tbody>
</table>
11. Are the findings convincing?
For example:
- Are the findings clearly presented?
- Are the findings internally coherent?
- Are extracts from the original data included?
- Are the data appropriately referenced?
- Is the reporting clear and coherent?

12. Are the findings relevant to the aims of the study?

13. Conclusions
For example:
- How clear are the links between data, interpretation and conclusions?
- Are the conclusions plausible and coherent?
- Have alternative explanations been explored and discounted?
- Does this enhance understanding of the research topic?
- Are the implications of the research clearly defined?

Is there adequate discussion of any
### Ethics

14. **How clear and coherent is the reporting of ethics?**

For example:

- Have ethical issues been taken into consideration?
- Are they adequately discussed e.g. do they address consent and anonymity?
- Have the consequences of the research been considered i.e. raising expectations, changing behaviour?
- Was the study approved by an ethics committee?

<table>
<thead>
<tr>
<th>Appropriate</th>
<th>Inappropriate</th>
<th>Not sure/not reported</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

**Overall assessment**

As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)

<table>
<thead>
<tr>
<th>++</th>
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<tbody>
<tr>
<td></td>
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</tbody>
</table>

**Comments:**

<table>
<thead>
<tr>
<th><strong>Study identification:</strong> (Include full citation details)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th><strong>Study design:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Refer to the glossary of study designs (appendix D) and the algorithm for classifying experimental and observational study designs (appendix E) to best describe the paper's underpinning study design</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Guidance topic:</strong></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th><strong>Assessed by:</strong></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th><strong>Section 1: Population</strong></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th><strong>1.1 Is the source population or source area well described?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the country (e.g. developed or non-developed, type of healthcare system), setting (primary schools, community centres etc.), location (urban, rural), population demographics etc. adequately described?</td>
</tr>
<tr>
<td>+</td>
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<tr>
<td>−</td>
</tr>
<tr>
<td>NR</td>
</tr>
<tr>
<td>NA</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>1.2 Is the eligible population or area representative of the source population or area?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the recruitment of individuals, clusters or areas well defined (e.g. advertisement, birth register)?</td>
</tr>
<tr>
<td>+</td>
</tr>
<tr>
<td>−</td>
</tr>
<tr>
<td>NR</td>
</tr>
<tr>
<td>NA</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>1.3 Do the selected participants or areas represent the eligible population or area?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the method of selection of participants from the</td>
</tr>
<tr>
<td>+</td>
</tr>
</tbody>
</table>
eligible population well described?  
What % of selected individuals or clusters agreed to participate? Were there any sources of bias?  
Were the inclusion or exclusion criteria explicit and appropriate?

<table>
<thead>
<tr>
<th>Section 2: Method of allocation to intervention (or comparison)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Allocation to intervention (or comparison). How was selection bias minimised?</td>
</tr>
<tr>
<td>Was allocation to exposure and comparison randomised? Was it truly random ++ or pseudo-randomised + (e.g. consecutive admissions)?</td>
</tr>
<tr>
<td>If not randomised, was significant confounding likely (−) or not (+)?</td>
</tr>
<tr>
<td>If a cross-over, was order of intervention randomised?</td>
</tr>
<tr>
<td>++</td>
</tr>
<tr>
<td>+</td>
</tr>
<tr>
<td>−</td>
</tr>
<tr>
<td>NR</td>
</tr>
<tr>
<td>NA</td>
</tr>
</tbody>
</table>

| 2.2 Were interventions (and comparisons) well described and appropriate? |
| Were interventions and comparisons described in sufficient detail (i.e. enough for study to be replicated)? |
| Was comparisons appropriate (e.g. usual practice rather than no intervention)? |
| ++ | Comments: |
| + | |
| − | |
| NR | |
| NA | |

<p>| 2.3 Was the allocation concealed? |
| Could the person(s) determining allocation of participants or clusters to intervention or comparison groups have influenced the allocation? |
| Adequate allocation concealment (++ would include centralised allocation or computerised allocation systems. |
| ++ | Comments: |
| + | |
| − | |
| NR | |
| NA | |</p>
<table>
<thead>
<tr>
<th>2.4 Were participants or investigators blind to exposure and comparison?</th>
<th>++ Comments:</th>
</tr>
</thead>
</table>
| Were participants and investigators – those delivering or assessing the intervention kept blind to intervention allocation? (Triple or double blinding score ++)

If lack of blinding is likely to cause important bias, score −. | + + |

NR
NA

<table>
<thead>
<tr>
<th>2.5 Was the exposure to the intervention and comparison adequate?</th>
<th>++ Comments:</th>
</tr>
</thead>
</table>
| Is reduced exposure to intervention or control related to the intervention (e.g. adverse effects leading to reduced compliance) or fidelity of implementation (e.g. reduced adherence to protocol)?

Was lack of exposure sufficient to cause important bias? | + + |

NR
NA

<table>
<thead>
<tr>
<th>2.6 Was contamination acceptably low?</th>
<th>++ Comments:</th>
</tr>
</thead>
</table>
| Did any in the comparison group receive the intervention or vice versa?

If so, was it sufficient to cause important bias?

If a cross-over trial, was there a sufficient wash-out period between interventions? | + + |

NR
NA

<table>
<thead>
<tr>
<th>2.7 Were other interventions similar in both groups?</th>
<th>++ Comments:</th>
</tr>
</thead>
</table>
| Did either group receive additional interventions or have services provided in a different manner?

Were the groups treated equally by researchers or other professionals?

Was this sufficient to cause important bias? | + + |

NR
NA

<table>
<thead>
<tr>
<th>2.8 Were all participants accounted for at study</th>
<th>++ Comments:</th>
</tr>
</thead>
</table>

++
**Conclusion?**

Were those lost-to-follow-up (i.e. dropped or lost pre-, during or post-intervention) acceptably low (i.e. typically <20%)?

Did the proportion dropped differ by group? For example, were drop-outs related to the adverse effects of the intervention?

<table>
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<th>NA</th>
</tr>
</thead>
</table>

**2.9 Did the setting reflect usual UK practice?**

Did the setting in which the intervention or comparison was delivered differ significantly from usual practice in the UK? For example, did participants receive intervention (or comparison) condition in a hospital rather than a community-based setting?

<table>
<thead>
<tr>
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<th>NR</th>
<th>NA</th>
</tr>
</thead>
</table>

**2.10 Did the intervention or control comparison reflect usual UK practice?**

Did the intervention or comparison differ significantly from usual practice in the UK? For example, did participants receive intervention (or comparison) delivered by specialists rather than GPs? Were participants monitored more closely?

<table>
<thead>
<tr>
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<th>NA</th>
</tr>
</thead>
</table>

**Section 3: Outcomes**

**3.1 Were outcome measures reliable?**

Were outcome measures subjective or objective (e.g. biochemically validated nicotine levels ++ vs self-reported smoking −)?

How reliable were outcome measures (e.g. inter- or intra-rater reliability scores)?

Was there any indication that measures had been validated (e.g. validated against a gold standard measure)?

<table>
<thead>
<tr>
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<th>NR</th>
<th>NA</th>
</tr>
</thead>
</table>
or assessed for content validity)?

<table>
<thead>
<tr>
<th>3.2 Were all outcome measurements complete?</th>
<th>++</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were all or most study participants who met the defined study outcome definitions likely to have been identified?</td>
<td>+</td>
<td>-</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.3 Were all important outcomes assessed?</th>
<th>++</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were all important benefits and harms assessed?</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td>Was it possible to determine the overall balance of benefits and harms of the intervention versus comparison?</td>
<td>++</td>
<td>Comments:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.4 Were outcomes relevant?</th>
<th>++</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where surrogate outcome measures were used, did they measure what they set out to measure? (e.g. a study to assess impact on physical activity assesses gym membership – a potentially objective outcome measure – but is it a reliable predictor of physical activity?)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.5 Were there similar follow-up times in exposure and comparison groups?</th>
<th>++</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>If groups are followed for different lengths of time, then more events are likely to occur in the group followed-up for longer distorting the comparison. Analyses can be adjusted to allow for differences in length of follow-up (e.g. using person-years).</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>3.6 Was follow-up time meaningful?</th>
<th>++</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question</td>
<td>Rating</td>
<td>Comments</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------</td>
<td>----------</td>
</tr>
<tr>
<td>Was follow-up long enough to assess long-term benefits or harms?</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Was it too long, e.g. participants lost to follow-up?</td>
<td>−</td>
<td></td>
</tr>
<tr>
<td>Was follow-up long enough to assess long-term benefits or harms?</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Was it too long, e.g. participants lost to follow-up?</td>
<td>−</td>
<td></td>
</tr>
</tbody>
</table>

**Section 4: Analyses**

### 4.1 Were exposure and comparison groups similar at baseline? If not, were these adjusted?  

Were there any differences between groups in important confounders at baseline?  

If so, were these adjusted for in the analyses (e.g. multivariate analyses or stratification).  

Were there likely to be any residual differences of relevance?  

<table>
<thead>
<tr>
<th>Rating</th>
<th>Comments</th>
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<tbody>
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<td>NR</td>
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<td>NA</td>
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</tbody>
</table>

### 4.2 Was intention to treat (ITT) analysis conducted?  

Were all participants (including those that dropped out or did not fully complete the intervention course) analysed in the groups (i.e. intervention or comparison) to which they were originally allocated?  

<table>
<thead>
<tr>
<th>Rating</th>
<th>Comments</th>
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<tbody>
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<tr>
<td>NR</td>
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<td>NA</td>
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</tbody>
</table>

### 4.3 Was the study sufficiently powered to detect an intervention effect (if one exists)?  

A power of 0.8 (that is, it is likely to see an effect of a given size if one exists, 80% of the time) is the conventionally accepted standard.  

Is a power calculation presented? If not, what is the expected effect size? Is the sample size adequate?  

<table>
<thead>
<tr>
<th>Rating</th>
<th>Comments</th>
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</thead>
<tbody>
<tr>
<td>++</td>
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<td>+</td>
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<td>−</td>
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</tr>
<tr>
<td>NR</td>
<td></td>
</tr>
<tr>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>4.4 Were the estimates of effect size given or calculable?</td>
<td>++</td>
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<tr>
<td>---</td>
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</tr>
<tr>
<td>Were effect estimates (e.g. relative risks, absolute risks) given or possible to calculate?</td>
<td>+</td>
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<td></td>
<td>−</td>
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<td></td>
<td>NR</td>
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<td>NA</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>4.5 Were the analytical methods appropriate?</th>
<th>++</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were important differences in follow-up time and likely confounders adjusted for?</td>
<td>+</td>
<td></td>
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<td></td>
<td>−</td>
<td></td>
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<td>NA</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>4.6 Was the precision of intervention effects given or calculable? Were they meaningful?</th>
<th>++</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were confidence intervals or p values for effect estimates given or possible to calculate?</td>
<td>+</td>
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<td></td>
<td>NA</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Were CI's wide or were they sufficiently precise to aid decision-making? If precision is lacking, is this because the study is under-powered?</th>
<th>+</th>
<th></th>
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</thead>
<tbody>
<tr>
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<td>NR</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Section 5: Summary</th>
<th>++</th>
<th>Comments:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>5.1 Are the study results internally valid (i.e. unbiased)?</th>
<th>++</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>How well did the study minimise sources of bias (i.e. adjusting for potential confounders)?</td>
<td>+</td>
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<tr>
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</tbody>
</table>
5.2 Are the findings generalisable to the source population (i.e. externally valid)?

Are there sufficient details given about the study to determine if the findings are generalisable to the source population? Consider: participants, interventions and comparisons, outcomes, resource and policy implications.

| Comments: | ++ | + | − |

The overall assessment from the qualitative checklist was included to allow comparisons across studies using different methodologies:

<table>
<thead>
<tr>
<th>Overall assessment</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)</td>
<td>++</td>
</tr>
</tbody>
</table>
Appendix 4. Quality checklist ratings for all reviewed studies.

Table 1. Qualitative studies.

<table>
<thead>
<tr>
<th>Study</th>
<th>Theoretical approach</th>
<th>Study design</th>
<th>Trustworthiness</th>
</tr>
</thead>
<tbody>
<tr>
<td>de la Iglesia Mayol (2006)</td>
<td>Appropriate</td>
<td>Clear</td>
<td>Not sure/ inadequately reported</td>
</tr>
<tr>
<td>Mee (2010)</td>
<td>Appropriate</td>
<td>Mixed</td>
<td>Indefensible</td>
</tr>
<tr>
<td>Sonson &amp; Stainton (1990)</td>
<td>Inappropriate</td>
<td>Mixed</td>
<td>Indefensible</td>
</tr>
<tr>
<td>Smith &amp; Forrester-Jones (2014)</td>
<td>Appropriate</td>
<td>Clear</td>
<td>Not sure</td>
</tr>
</tbody>
</table>

Table 1. Qualitative studies continued.

<table>
<thead>
<tr>
<th>Analysis</th>
<th>Study</th>
<th>Ethics</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>de la Iglesia Mayol (2006)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not rigorous</td>
<td>Poor</td>
<td>Unreliable</td>
</tr>
<tr>
<td></td>
<td>Mee (2010)</td>
<td>Not rigorous</td>
<td>Poor</td>
</tr>
<tr>
<td></td>
<td>Sinson &amp; Stainton (1990)</td>
<td>Not rigorous</td>
<td>Poor</td>
</tr>
<tr>
<td></td>
<td>Smith &amp; Forrester-Jones (2014)</td>
<td>Rigorous</td>
<td>Rich</td>
</tr>
</tbody>
</table>

135
Table 2. Quantitative studies. N.B. NA = Not applicable; NR = Not reported.

<table>
<thead>
<tr>
<th>Study</th>
<th>Section 1 - Population</th>
<th>Section 2 – Allocation to Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1.1.</td>
<td>1.2.</td>
</tr>
<tr>
<td>Bailey et al (2001)</td>
<td>-</td>
<td>NR</td>
</tr>
<tr>
<td>Hall &amp; Hollins (1996)</td>
<td>-</td>
<td>NR</td>
</tr>
<tr>
<td>Hall &amp; Minnes (1999)</td>
<td>+</td>
<td>NR</td>
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<td>Jones et al (2015)</td>
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<td>Laking (1988)</td>
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<td>Nosse &amp; Gavin (1991)</td>
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<tr>
<td>Russell &amp; Ayer (1988)</td>
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136
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<tr>
<th>Study</th>
<th>Section 3 – Outcomes</th>
<th>Section 4 – Analyses</th>
<th>Section 5 - Summary</th>
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<td>Bailey et al (2001)</td>
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</table>

Table 2. Quantitative studies continued. N.B. NA = Not applicable; NR = Not reported.
| Study                           | Score | Notes 1 | Presence | Notes 2 | Presence | Notes 3 | Presence | Notes 4 | Presence | Notes 5 | Presence | Notes 6 | Presence | Notes 7 |Presence | Notes 8 | Presence | Notes 9 | Presence | Notes 10 |
|--------------------------------|-------|---------|----------|---------|----------|---------|----------|---------|----------|---------|----------|---------|----------|---------|----------|---------|----------|---------|----------|---------|----------|
| Laking (1988)                  | +     | NA      | NA       | +       | NA       | NA      | NR       | NA      | NR       | NR      | NR       | NR      | +        | +        | +        | +        |
| McConkey et al (1983)          | -     | +       | NA       | +       | NA       | +       | NA       | NA      | NA       | +       | +        | +       | +        | +        | +        | +        |
| May (1991)                     | -     | ++      | NA       | +       | NA       | NA      | NA       | NR      | NR       | NR      | NR       | NR      | -        | +        | -        | +        |
| May et al (1994)               | -     | +       | NA       | +       | NA       | NA      | NA       | NR      | NR       | NR      | +        | -        | -        | +        | +        | +        |
| Nosse & Gavin (1991)           | +     | +       | NA       | +       | NA       | NA      | NR       | NA      | NR       | NR      | NA       | +        | +        | +        | +        | +        |
| Russell & Ayer (1988)          | ++    | NA      | NA       | ++      | NA       | NA      | NR       | NR      | NR       | NR      | NR       | NR      | +        | +        | -        | +        |
| Shields & Taylor (2014)        | +     | ++      | NA       | +       | NA       | NA      | +        | NA      | ++       | NR      | NR       | ++      | ++       | ++       | ++       | ++       |
| Sinai et al (2013)             | ++    | +       | NA       | +       | NA       | NA      | NR       | ++      | NR       | NR      | NR       | NR      | +        | +        | +        | +        |
| Varughese & Luty (2010)        | ++    | NR      | NA       | +       | NA       | NA      | NR       | NA      | NR       | +       | NR       | NR      | +        | +        | +        | +        |
| Varughese et al (2011)         | ++    | +       | NA       | +       | NA       | NA      | NR       | NA      | NR       | NR      | NR       | NR      | +        | +        | +        | +        |
| Walker & Scior (2013)          | +     | +       | NA       | ++      | ++       | +       | NA       | NA      | ++       | ++       | ++       | ++       | ++       | ++       | ++       | ++       |
### Appendix 5. Data extraction form.

<table>
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<td><strong>Participants</strong> (including demographic information)</td>
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<td><strong>Intervention(s)</strong></td>
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<td><strong>Design</strong></td>
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<td><strong>Measure(s) of effectiveness of intervention</strong> (qualitative/quantitative/mixed)</td>
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<td><strong>Analysis</strong></td>
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<td><strong>Findings related to perception/attitude change</strong></td>
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</table>
Appendix 6. Author guidelines for ‘Journal of Community Psychology’ (empirical paper).

Contents
Submission
2. Aims and Scope
3. Preparing Your Submission
4. Editorial Policies and Ethical Considerations
5. Author Licensing
6. Publication Process After Acceptance
7. Post Publication
8. Editorial Office Contact Details

1. SUBMISSION
Thank you for your interest in Journal of Community Psychology. Note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.
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University of Pennsylvania
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Philadelphia, PA 19104-3309
Tel: 215-746-6717
Fax: 215-349-8715
E-mail: mblank2@mail.med.upenn.edu
USA
We look forward to your submission.

2. AIMS AND SCOPE
The Journal of Community Psychology is a peer-reviewed journal devoted to research, evaluation, assessment, and intervention. Although review articles that deal with human behavior in community settings are occasionally accepted, the journal’s primary emphasis is on empirical work that is based in or informs studies to understand community factors that influence, positively and negatively, human development, interaction, and functioning. Articles of interest include descriptions and evaluations of service programs and projects; studies of youth, parenting, and family development; methodological studies for the identification and systematic alteration of risks; and protective factors for emotional and behavioral disorders and for positive development.
The journal also publishes the results of projects that inform processes relevant to the
design of community-based interventions including strategies for gaining entry, engaging a community in participatory action research, and creating sustainable interventions that remain after project development and empirical work are completed.

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The title page should contain:
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- (ii) a short running title of less than 40 characters;
- (iii) the full names of the authors;
- (iv) the author's institutional affiliations at which the work was carried out;
- (v) acknowledgments
- (vi) three to four referees (see below).

Authors will be required to include the names, institutions, e-mail addresses, and research specialties of three to four persons outside the author's institution who have not collaborated with the author(s) in the past 5 years and who are qualified to referee the paper. An effort will be made to obtain at least one referee from this list. The present address of any author, if different from that where the work was carried out, should be supplied in a footnote.

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You will be asked to provide a conflict of interest statement during the submission process. See the section ‘Conflict of Interest’ in the Editorial Policies and Ethical Considerations section for details on what to include in this section. Please ensure you liaise with all co-authors to confirm agreement with the final statement.

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As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors. The main text file should be presented in the following order:
- (i) title, abstract and key words,
- (ii) main text
- (iii) references
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The Abstract should be divided into the following sections 'Aims', 'Methods, Results' and 'Conclusion'; it should not exceed 150 words for articles and brief reports.

Keywords
Please provide seven keywords. Keywords should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at https://www.nlm.nih.gov/mesh/.

Main text
As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors. The journal uses British/US spelling, however authors may submit using either option as spelling of accepted papers is converted during the production process. Footnotes to the text are not allowed and any such material should be incorporated into the text as parenthetical matter.

References
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

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

Internet Document
**Endnotes**

Endnotes should be placed as a list at the end of the paper only, not at the foot of each page. They should be numbered in the list and referred to in the text with consecutive, superscript Arabic numerals. Keep endnotes brief; they should contain only short comments tangential to the main argument of the paper.

**Footnotes**

Footnotes should be placed as a list at the end of the paper only, not at the foot of each page. They should be numbered in the list and referred to in the text with consecutive, superscript Arabic numerals. Keep footnotes brief: they should contain only short comments tangential to the main argument of the paper and should not include references.

**Tables**

Tables should be self-contained and complement, but not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

**Figure Legends**

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

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Although we encourage authors to send us the highest-quality figures possible, for peer-review purposes we are happy to accept a wide variety of formats, sizes, and resolutions.

Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

**Color figures**

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Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text.
Supporting Information
Supporting information is information that is not essential to the article but that provides greater depth and background. It is hosted online, and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc. Click here for Wiley’s FAQs on supporting information.

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- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website at http://www.bipm.fr for more information about SI units.
- **Numbers:** numbers under 10 are spelled out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
- **Trade Names:** Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name, and the name and location of the manufacturer, in parentheses.

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We require that clinical trials are prospectively registered in a publicly accessible database and clinical trial registration numbers should be included in all papers that report their results. Please include the name of the trial register and your clinical trial registration number at the end of your abstract. If your trial is not registered, or was registered retrospectively, please explain the reasons for this.
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Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. We encourage authors to adhere to the following research reporting standards.

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- PRISMA
- PRISMA-P
- STROBE
- CARE
- COREQ
- STARD and TRIPOD
- CHEERS
- the equator network
- Future of Research Communications and e-Scholarship (FORCE11)
- ARRIVE guidelines
- National Research Council's Institute for Laboratory Animal Research guidelines: the Gold Standard Publication Checklist from Hooijmans and colleagues
- Minimum Information Guidelines from Diverse Bioscience Communities (MIBBI) website; Biosharing website
- REFLECT statement

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Upon its first use in the title, abstract and text, the common name of a species should be followed by the scientific name (genus, species and authority) in parentheses. For well-known species, however, scientific names may be omitted from article titles. If no common name exists in English, the scientific name should be used only.

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Sequence variants should be described in the text and tables using both DNA and protein designations whenever appropriate. Sequence variant nomenclature must follow the current HGVS guidelines; see [http://varnomen.hgvs.org/](http://varnomen.hgvs.org/), where examples of acceptable nomenclature are provided.

**Nucleotide Sequence Data**

Nucleotide sequence data can be submitted in electronic form to any of the three major collaborative databases: DDBJ, EMBL or GenBank. It is only necessary to submit to one database as data are exchanged between DDBJ, EMBL and GenBank on a daily basis. The suggested wording for referring to accession-number information is: ‘These sequence data have been submitted to the DDBJ/EMBL/GenBank databases under accession number U12345’. Addresses are as follows:

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- EMBL Nucleotide Sequence Submissions [http://www.ebi.ac.uk](http://www.ebi.ac.uk)

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2. Been involved in drafting the manuscript or revising it critically for important intellectual content;
3. Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; and
4. Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Email: chris.jones@sheridan.com

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8. EDITORIAL OFFICE CONTACT DETAILS
JCOP Editorial Office Email: jcopeditorial@wiley.com
Author Guidelines updated Mar 2017
Appendix 7. Documentation of ethical approval.

Removed for hard binding
Appendix 8. Recruitment flyer for PwID.

Research with Danielle

What is being part of [theatre company name] like?

Participants Needed!

- I would like to talk to people about what it’s like being part of [theatre company name].
- I would like to find out if anything has changed in your life since you joined.
- I would meet with you first to talk about the research, and make sure you know what taking part would involve.
- I would then meet with you for an interview. This would last for around 1 hour, and would involve answering some questions.

If you want to find out more...

Speak to [removed for anonymity]

Contact Danielle on the phone:

Or on the phone: [removed for anonymity]

Or e-mail her: [removed for anonymity]

Thank you for your interest!
Appendix 9. Recruitment flyer for significant others and community members.

**Research Study:** Changes in understandings and perceptions of people involved with [theatre company name]

**Participants Needed!**

I am doing some research at [theatre company name] as part of a Doctorate in Clinical Psychology at the University of Hull.

I am hoping to run a focus group with significant people in [theatre company name] member’s lives, who might be a parent, relative, friend, member of staff or somebody else.

I also want to run a focus group with members of the wider community who are involved with [theatre company name] in some way.

The focus groups will discuss what impact they think [theatre company name] has, and whether there have been any changes in the perceptions of the participants through being involved in the organisation.

The focus groups will take place at the [theatre company name] premises on:

**[Insert date and time]** For significant people in member’s lives

**[Insert date and time]** For members of the wider community

If you are available at that time and would like to know more, please contact the researcher:

Danielle Dickinson
Via telephone: [removed for anonymity]
Via e-mail: d.dickinson@2014.hull.ac.uk

Or you can speak [removed for anonymity]
Via telephone: [removed for anonymity]
Via e-mail: [removed for anonymity]

Thank you for your interest!
Appendix 10. Participant information sheet for members with ID.

Information about the research

Title of the Study: Changes in understandings and perceptions of individuals, significant others and community members involved in a theatre group for people with intellectual disabilities.

We would like to invite you to take part in a research study. This sheet will explain why the research is being done and what would happen if you took part. Someone will go through the information sheet with you and answer any questions you have before you decide if you want to take part. This should take around 30 minutes.

What is the research about?
The research is about the impact of [theatre company name] on members’ lives. We are interested in what’s changed for people since they became involved in [theatre company name], particularly in how they see themselves and how they think others see them. We are also going to talk to the important people in [theatre company name] member’s lives to see what impact they think [theatre company name] has. This might be someone important to you, if they ask to take part. We will also talk to members of the community who follow [theatre company name].

Why is the research being done?
This research is part of the Clinical Psychology training programme at the University of Hull. It is hoped this research will show what changes [theatre company name] has brought to people’s lives. It may also show what impact [theatre company name] has
had on significant people in member’s lives, and also the wider community. The research might also show how similar companies could help other people.

**Why am I asking you to take part in the research study?**

You have been asked to take part in the research because you are a member of [theatre company name].

**Do I have to take part?**

No. It is up to you whether you want to take part. We will tell you about the research and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You will be given a copy of the information sheet and the signed consent form.

**What will happen if I take part?**

- If you want to take part, you will be interviewed once.
- This will involve sitting on your own with the researcher and being asked some questions about your life before you joined [theatre company name], and ways your life is different now.
- You can answer all of the questions or choose not to answer some if you don’t want to.
- The interviews will take place at either the [theatre company name] premises, where you live or somewhere else it is easy for you to get to.
- The interview will be at a date and time that you are available.
- The interviews will last for about an hour.
- The interviews will be recorded so that they can be listened to and typed up later.
• All of the recordings and typed up interviews will be kept locked away and have no personal details on them.

**What are the possible advantages/disadvantages of taking part?**

If there were difficult things that happened before you joined [theatre company name], it might be hard to talk about these things. It could make you feel sad or angry. If this happens, you will be given information about where you can get some support. You will be asked if you feel you need this after the interview or you can leave the interview at any time if you would like. If we become worried about your wellbeing, we might have to inform your GP. This will be talked about first. We might also speak to [removed for anonymity] at [theatre company name] about what has happened.

If you take part, you will be helping people to understand how [theatre company name] can affect people’s lives.

**What happens if I want to stop?**

If you agree to join the research and then change your mind, you can. You do not need to give a reason for this. However, you will need to let the researcher know before the data is analysed.

**If you are unhappy?**

If you are worried about any part of this study, you can speak to the researcher who will try to answer your questions [Danielle Dickinson, contact number removed for binding]. If you are still unhappy and want to speak to someone else, you can do this by contacting the Associate Dean for Research, Faculty of Health and Social Care, University of Hull, Cottingham Road, Hull, HU6 7RX. 01482 463 342.
Will my details be kept confidential?

- All of your information will be stored securely in a locked cabinet and eventually destroyed.
- As this research is being used for a university course, this means that the research will be sent for assessment to the University of Hull. The research will also be sent to a journal, which means that anybody else who is interested in the research will be able to read it.
- It will not be possible for anyone to know who you are from the research as all of your details are taken out, and different names are used.
- However, the only time we may need to break this privacy is if we become concerned about your safety or someone else’s. We will talk to you about this, and think about who we need to talk to. We will also speak to [removed for anonymity] at [theatre company name].

Who is reviewing this research?

All research at the University of Hull is checked by a group of people, called a Research Ethics Committee. This study has been looked at and agreed by the Faculty of Health and Social Care Research Ethics Committee.

Further information and contact details

If you would like any further information about this research, please contact me:

Danielle Dickinson

The Department of Health and Psychological Wellbeing

Aire Building, University of Hull

Cottingham Road

Hull
This research project is being supervised by:

Nick Hutchinson

The Department of Health and Psychological Wellbeing

Aire Building, University of Hull

Cottingham Road

Hull

HU6 7RX

Telephone: 01482 464804

E-mail: N.Hutchinson@hull.ac.uk

Information Sheet

**Being part of [theatre company name]**

My name is Danielle Dickinson. This information sheet is about my research.

You have been given this information sheet because you might be interested in taking part in the research.

**What is the research about?**

I am going to talk to lots of members of [theatre company name].

I want to find out what it is like being part of [theatre company name].
I want to find out if anything has changed in your life since you joined.

(Picture removed for anonymity)

I am also going to talk to the important people in [theatre company name] member’s lives to see what they think about [theatre company name]. This might be someone important to you, if they ask to take part.

I will also speak to members of the community who follow [theatre company name].

**Why is the research being done?**

I want to see what impact being involved in [theatre company name] has on peoples’ lives.

I want to see whether companies like [theatre company name] might help other people.

![Theatre scene with audience and actors on stage]

**What will you have to do?**

I would like to meet with you on your own and ask you some questions.
This will last for about an hour.

I will record what we talk about. This will help me remember has been said.

But what we talk about will be private.

Unless I am worried about your safety or someone else’s.

**Do you have to take part?**

No. You can say “Yes” or “No”.
You can say “Yes” and then change your mind.

It is okay if you say “No”.

**Who can you talk to if you want more information or you are worried about taking part?**

You can ring me on (contact number removed for binding)

You can also speak to [removed for anonymity] when you are at [theatre company name].

*(Picture removed for anonymity)*

We will try and answer all of your questions.
Or you can talk about taking part with anyone you feel comfortable with, like a family member or friend.
Appendix 12. Participant information sheet for significant others.

Information about the research

Title of the Study: Changes in understandings and perceptions of individuals, significant others and community members involved in a theatre group for people with intellectual disabilities.

We would like to invite you to take part in our research study. This sheet will explain why the research is being done and what would happen if you took part. Someone will go through this information sheet with you via telephone, and answer any questions you have before you decide if you want to take part. This should take around 15 minutes.

What is the research about?

The research is being conducted as part of the Doctorate in Clinical Psychology programme at the University of Hull. The research aims to gather information about the impact of [theatre company name], for members, the significant people in [theatre company name] members’ lives, and also the wider community. We are aware that some people hold negative perceptions of intellectual disabilities, which can lead to individuals having difficult experiences in society, and also limited expectations placed on what they can achieve. We want to find out if involvement in organisations such as [theatre company name] can have any impact on this. We are interested in whether anything has changed for you through having someone you care about involved in [theatre company name], and what you think has changed for that person, in terms of how they perceive themselves and how they think others perceive them.
Why are we inviting you to take part?

We are inviting you to take part because you are a significant person in a [theatre company name] member’s life.

Do I have to take part?

It is up to you to whether you would like to take part. We will tell you about the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You will be given a copy of the information sheet and the signed consent form. You are free to stop the research at any time, without giving a reason.

What will happen if I take part?

If you want to take part, you will be involved in a “focus group”. This will involve having a discussion around some questions that the researcher will provide with between 3 and 7 other people who are also significant people in a [theatre company name] members’ life. You can choose to be involved in the discussions around as many or as few questions as you feel comfortable with. The focus group will take place at the [theatre company name] premises on [insert date and time of focus group]. The focus group will last between an hour and an hour and a half, with a break at around half way. The focus group will be recorded so it can be listened to and typed up later. All of the recordings and typed up interviews will be kept locked away, and have no personal details on them.

What are the possible advantages/disadvantages of taking part?

Discussing perceptions and what things were like before the person you care about joined [theatre company name] might involve remembering difficult situations, and bring up some hard feelings for you. If this happens, you will be given details of where
you can get further support. You will be asked if you feel you need this after the focus group or you can leave the focus group at any time if you would like. If we become worried about your wellbeing we might have to inform your GP, and this will be talked about before we do this.

If you take part, you would be contributing to an under-researched area around the impact of organisations such as [theatre company name] on the significant people in members’ lives, as we are aiming to publish the research when it is completed. Showing the impact of organisations such as [theatre company name] may also demonstrate what might be helpful for other people who might be perceived negatively in society.

**What happens if I want to stop?**

If you agree to join the research and then change your mind, you can. However, this will need to be done before the focus group data is analysed.

**If you are unhappy?**

If you are worried about any part of this study, you can speak to the researcher who will try to answer your questions [Danielle Dickinson, contact number removed for binding]. If you are still unhappy and wish to take this further, you can do this by contacting the Associate Dean for Research, Faculty of Health and Social Care, University of Hull, Cottingham Road, Hull, HU6 7RX. 01482 463 342.

**Will my details be kept confidential?**

All typed focus groups and information about you will be stored securely in a locked cabinet, in keeping with University guidelines, for up to ten years, after which time it will be destroyed.
As this research is being used for a university course, it will be sent for assessment to the University of Hull. The research will also be sent to a journal, which means that anybody else who is interested in the research will be able to read it. It will not be possible for anyone to know who you are from the research as all of your details are taken out, and different names are used. However, the only time we may need to break this confidentiality is in the unlikely event that we become concerned about the safety of you or somebody else. We will discuss this with you, and consider what to do next.

**Who is reviewing this research?**
All research at the University of Hull is checked by the Research Ethics Committee. This study has been looked at and agreed by the Faculty of Health and Social Care Research Ethics Committee.

**Further information and contact details**
Please feel free to discuss the research with the person you care about, before deciding whether you want to take part.

If you would like any further information about this research, please contact me:

Danielle Dickinson
The Department of Health and Psychological Wellbeing
Aire Building, University of Hull
Cottingham Road
Hull
HU6 7RX

Telephone: *Removed for binding*
E-mail: d.dickinson@2014.hull.ac.uk

This research project is being supervised by:

Nick Hutchinson

The Department of Health and Psychological Wellbeing

Aire Building, University of Hull

Cottingham Road

Hull

HU6 7RX

Telephone: 01482 464804

E-mail: N.Hutchinson@hull.ac.uk
Appendix 13. Participant information sheet for community members.

Information about the research

Title of the Study: Changes in understandings and perceptions of individuals, significant others and community members involved in a theatre group for people with intellectual disabilities.

We would like to invite you to take part in our research study. This sheet will explain why the research is being done and what would happen if you took part. **Someone will go through this information sheet with you via telephone, and answer any questions you have before you decide if you want to take part.** This should take around 15 minutes.

What is the research about?

The research is being conducted as part of the Doctorate in Clinical Psychology programme at the University of Hull. The research aims to gather information about the impact of [theatre company name], for members, the significant people in [theatre company name] members’ lives, and also the wider community. We are aware that some people hold negative perceptions of intellectual disabilities, which can lead to individuals having difficult experiences in society, and also limited expectations placed on what they can achieve. We want to find out if involvement in organisations such as [theatre company name] can have any impact on this. We are interested in whether anything has changed for you through following [theatre company name] over time. We are particularly interested in changes in perceptions.
Why are we inviting you to take part?

We are inviting you to take part because you are a member of the community who is involved with [theatre company name] in some way.

Do I have to take part?

It is up to you to whether you would like to take part. We will tell you about the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You will be given a copy of the information sheet and the signed consent form. You are free to stop the research at any time, without giving a reason.

What will happen if I take part?

If you want to take part, you will be involved in a “focus group”. This will involve having a discussion around some questions that the researcher will provide with between 3 and 7 other people who are also members of the community who are involved with [theatre company name] in some way. You can choose to be involved in the discussions around as many or as few questions as you feel comfortable with. The focus group will take place at the [theatre company name] premises on [insert date and time of focus group]. The focus group will last between an hour and an hour and a half, with a break at around half way. The focus group will be recorded so it can be listened to and typed up later. All of the recordings and typed up interviews will be kept locked away, and have no personal details on them.

What are the possible advantages/disadvantages of taking part?

Discussing perceptions of intellectual disabilities is a sensitive subject, so it might bring up some difficult feelings for you. If this happens, you will be given details of where you can get further support. You will be asked if you feel you need this after the focus
group or you can leave the focus group at any time if you would like. If we become worried about your wellbeing we might have to inform your GP, and this will be talked about before we do this.

If you take part, you would be contributing to an under-researched area around the impact of organisations such as [theatre company name] on the local community, as we are aiming to publish the research when it is completed. Growing support for organisations such as [theatre company name] may also encourage similar charities to be set up in other communities.

**What happens if I want to stop?**
If you agree to join the research and then change your mind, you can. However, this will need to be done before the focus group data is analysed.

**If you are unhappy?**
If you are worried about any part of this study, you can speak to the researcher who will try to answer your questions [Danielle Dickinson, contact number removed for binding]. If you are still unhappy and wish to take this further, you can do this by contacting the Associate Dean for Research, Faculty of Health and Social Care, University of Hull, Cottingham Road, Hull, HU6 7RX. 01482 463 342.

**Will my details be kept confidential?**
All typed interviews and information about you will be stored securely in a locked cabinet, in keeping with University guidelines, for up to ten years, after which time it will be destroyed.
As this research is being used for a university course, it will be sent for assessment to the University of Hull. The research will also be sent to a journal, which means that anybody else who is interested in the research will be able to read it. It will not be possible for anyone to know who you are from the research as all of your details are taken out, and different names are used. However, the only time we may need to break this confidentiality is in the unlikely event that we become concerned about the safety of you or somebody else. We will discuss this with you, and consider what to do next.

**Who is reviewing this research?**

All research at the University of Hull is checked by the Research Ethics Committee. This study has been looked at and agreed by the Faculty of Health and Social Care Research Ethics Committee.

**Further information and contact details**

If you would like any further information about this research, please contact me:

Danielle Dickinson
The Department of Health and Psychological Wellbeing
Aire Building, University of Hull
Cottingham Road
Hull
HU6 7RX
Telephone: Removed for binding
E-mail: d.dickinson@2014.hull.ac.uk

This research project is being supervised by:

Nick Hutchinson
The Department of Health and Psychological Wellbeing
Aire Building, University of Hull
Cottingham Road
Hull
HU6 7RX
Telephone: 01482 464804
E-mail: N.Hutchinson@hull.ac.uk
Appendix 14. Consent form for members with ID.

Participant Number:

Consent Form

**Title of Project:** Changes in understandings and perceptions of individuals, significant others and community members involved in a theatre group for people with intellectual disabilities.

**Name of Researcher:** Danielle Dickinson

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 08/04/2016 (Version 3) for the above study. I have had the chance to think about the information, ask questions and have had these answered so that I understand.

2. I understand that taking part is voluntary and that I am free to withdraw up to the point of the data being analysed, without giving any reason and this will not affect my medical care or legal rights.

3. I confirm that direct quotes from the interview may be used in future publications and understand that they will not be linked to me.

4. I understand that some of the data collected during the research may be looked at by individuals from the University of Hull, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

5. I agree to take part in the interview part of the study.

6. I agree that the interview can be recorded.

**Name of Participant:** ______________________  **Date:** ______________  **Signature:** ______________________

__________________________    ______________    ___
Appendix 15. Consent form for members with ID – easy-read version.

Participant Number:

Consent Form

Name: _________________________________________    Date: _______________

Danielle Dickinson has talked to me about the research and why it is being done.

Yes  ☐  No  ☐  Not sure  ☐

I have had time to think about the research and I understand what the research will be about.

Yes  ☐  No  ☐  Not sure  ☐

I know that I do not have to do it and this is my choice.

Yes  ☐  No  ☐  Not sure  ☐

I know the things I talk about with Danielle will remain private unless she is worried about my safety or someone else’s.

Yes  ☐  No  ☐  Not sure  ☐

I am happy to talk to Danielle about being part of [theatre company name]. I am happy for the interview to be recorded.

Yes  ☐  No  ☐  Not sure  ☐

Signature: ____________________________________________________________
Appendix 16. Consent form for significant others and community members.

Participant Number:

Consent Form

Title of Project: Changes in understandings and perceptions of individuals, significant others and community members involved in a theatre group for people with intellectual disabilities.

Name of Researcher: Danielle Dickinson

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 08/04/2016 (Version 3) for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.

2. I understand that taking part is voluntary and that I am free to withdraw at any time without giving any reason up to the point of data transcription, without my legal rights being affected.

3. I understand that other people will be involved in the focus group, and I confirm that I will not divulge sensitive details or information about other participants from the discussions outside of the group.

4. I confirm that direct quotes that I have contributed in the focus groups may be used in future publications and understand that they will be anonymised.

5. I understand that some of the data collected during the research may be looked at by individuals from the University of Hull, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

6. I agree to take part in the interview part of the study and understand that my interview will be audio taped.

Name of Participant: __________________________ Date: ______________ Signature: __________________________

Participant Number: __________________________
Appendix 17. Demographic information sheet for members with ID.

Participant Number:

Information about you

Please tick ☑

1. What is your age in years?

..........................

2. Are you male or female?

Male ☐ Female ☐ Prefer not to say ☐

3. Which ethnic group describes you best?

☐ White British ☐ Other Asian background
☐ Other White background ☐ Black Caribbean and White
☐ Black British ☐ Black African and White
☐ Black African ☐ Asian and White
☐ Black Caribbean ☐ Other Dual Heritage
☐ Other Black background ☐ Chinese
☐ Indian ☐ Traveller
☐ Pakistani ☐ Bangladeshi
☐ Other Ethnic Group ☐ Prefer not to say

4. Where do you live?

☐ I live in my family home that I grew up in
☐ I live in a family member’s home
☐ I live in a residential home
☐ I live in supported housing
☐ I live with a friend/friends
☐ I live independently
☐ I live somewhere else. Please tell us more about this:

........................................................................................................................................

5. Around how long have you been a member of [theatre company name]?

☐ Less than 6 months
☐ 6 months-1 year
☐ 1-3 years
☐ 4-6 years
☐ 7-9 years
☐ More than 9 years

6. Which groups are you involved in at [theatre company name]? Please tick all that apply.
7. How often do you go to [theatre company name] each week?

☐ 1 time
☐ 2 times
☐ 3 times
☐ 4 times
☐ 5 times
☐ 6 or more times

Thank you for completing this questionnaire
Appendix 18. Demographic information sheet for significant others.

Participant Number:

Information about you

Please tick ✓

8. What is your age in years?

..........................

9. Are you male or female?

Male □ Female □ Prefer not to say □

10. Which ethnic group describes you best?

[Please select and mark with a '✓' the relevant options.]

- □ White British
- □ Other White background
- □ Black British
- □ Black African
- □ Black Caribbean
- □ Other Black background
- □ Indian
- □ Pakistani
- □ Other Ethnic Group
- □ Other Asian background
- □ Black Caribbean and White
- □ Black African and White
- □ Asian and White
- □ Other Dual Heritage
- □ Chinese
- □ Traveller
- □ Bangladeshi
- □ Prefer not to say

11. What is your relationship to the person involved in [theatre company name]?

[Please select and mark with a '✓' the relevant options.]

- □ Parent
- □ Sibling
- □ Other relative. Please specify:…………………………
- □ Guardian
- □ Carer
- □ Support worker
- □ Friend
- □ Other. Please specify:…………………………

12. Approximately how long has this person been a member of [theatre company name]?

[Please select and mark with a '✓' the relevant options.]

- □ Less than 6 months
- □ 6 months-1 year
- □ 1-3 years
- □ 4-6 years
- □ 7-9 years
- □ More than 9 years
13. In what ways are you involved in [theatre company name]? Please tick all that apply.

☐ On the mailing list
☐ Fundraiser
☐ Volunteer
☐ Donate to the charity
☐ Attend performances
☐ None of the above
☐ Other. Please specify:………………………………………………

Thank you for completing this questionnaire
Appendix 19. Demographic information sheet for community members.

Participant Number:

Information about you

Please tick ✓

14. What is your age in years?

....................................

15. Are you male or female?

Male ☐ Female ☐ Prefer not to say ☐

16. Which ethnic group describes you best?

☐ White British ☐ Other Asian background
☐ Other White background ☐ Black Caribbean and White
☐ Black British ☐ Black African and White
☐ Black African ☐ Asian and White
☐ Black Caribbean ☐ Other Dual Heritage
☐ Other Black background ☐ Chinese
☐ Indian ☐ Traveller
☐ Pakistani ☐ Bangladeshi
☐ Other Ethnic Group ☐ Prefer not to say

17. In what ways are you involved in [theatre company name]? Please tick all that apply.

☐ On the mailing list
☐ Fundraiser
☐ Volunteer
☐ Donate to the charity
☐ Attend performances
☐ None of the above
☐ Other. Please specify:....................................................

18. Approximately how long have you been involved with [theatre company name]?

☐ Less than 6 months
☐ 6 months-1 year
☐ 1-3 years
☐ 4-6 years
☐ 7-9 years
☐ More than 9 years
19. On average, how many [theatre company name] events do you attend per year?

- [ ] 0-2 events
- [ ] 3-4 events
- [ ] 5-6 events
- [ ] 7-8 events
- [ ] 9 or more events

20. Please say a little about how or why you became involved with [theatre company name].

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........................................................................................................................................
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........................................................................................................................................

Thank you for completing this questionnaire
Appendix 20. Interview schedule for members with ID.

Interview Schedule – PwID

The interview schedule will not be strictly followed, but rather, used to guide questions and the general direction of the interview.

Research Question
Changes in understandings and perceptions of individuals, significant others and community members involved in a theatre group for people with intellectual disabilities.

Interview aims:

- To investigate how PwID make sense of their involvement in a theatre company.
- To discover whether this has any impact on how PwID understand and perceive themselves, and how they think others understand and perceive them, or how they live their lives.

Questions

1. What was your life like before you joined [theatre company name]?

   Prompts Activities Living arrangements Employment Relationships Self-perceptions Others perceptions Behaviour of others (examples)

2. Is your life different since you joined [theatre company name]? In what ways?

   Prompts Activities Living arrangements Employment Relationships Self-perceptions Others perceptions Behaviour of others (examples)

3. How do these changes (if any) make you feel?

   Prompts Happy Sad Angry Scared Worried Excited Surprised (use visual aid in Appendix 21 if necessary)

4. Have these changes affected how you live your life in any way?
5. Why do you think being a member of [theatre company name] has changed your life in these ways?

**Prompts**
- Treated differently
- Opportunities – occupational/social

*Appendix 21.* Visual aid for emotions for interview.

![Visual Aid for Emotions](image-url)
Appendix 22. Focus group schedule for significant others.

Focus Group Schedule – Significant Others

The focus group schedule will not be strictly followed, but rather, used to guide questions and the general direction of the discussion.

Research Question
Changes in understandings and perceptions of individuals, significant others and community members involved in a theatre group for people with intellectual disabilities.

Focus group aims:

- To investigate how significant people in members of a theatre company’s lives make sense of their involvement with the theatre company.
- To discover whether this has any impact on the understandings and perceptions significant others have of PwID, or impacts on how they live their lives.

Questions

1. What impact do you think being involved in [theatre company name] has had on the person you care about?

   **Prompts**  Life changes  Self-perception  Others perceptions

2. What impact has the person you care about being involved in [theatre company name] had on you?

   **Prompts**  Perceptions of them  Expectations of achievement  Changes in behaviour  Impact upon person of these changes  Perceptions of ID Everyday life

3. What impact do you think having [theatre company name] as a local organisation has upon the wider community?

   **Prompts**  Perceptions of ID  Expectations of achievement  Stigma/discrimination  Isolation
4. Why do you think [*theatre company name*] has had/might have these impacts?

**Prompts**  On members  On significant others  On the wider community
Appendix 23. Focus group schedule for community members.

Focus Group Schedule – Community Members

The focus group schedule will not be strictly followed, but rather, used to guide questions and the general direction of the discussion.

Research Question
Changes in understandings and perceptions of individuals, significant others and community members involved in a theatre group for people with intellectual disabilities.

Focus group aims:

- To investigate how members of the wider community make sense of their involvement with a theatre company.
- To discover whether this has any impact on the understandings and perceptions community members have of PwID, or impacts on how they live their lives.

Questions

1. Why did you become involved with [theatre company name] initially?

   **Prompts**  Arts/theatre  Work-life  Previous experiences

2. What were your perceptions of people with intellectual disabilities before you got involved with [theatre company name]?

   **Prompts**  Activities  Living arrangements  Employment  Relationships  Expectations of achievement  Behaviour towards PwID

3. Where do you think these perceptions might have come from?

   **Prompts**  Family narratives  Societal messages  Media influences

4. Has being involved in [theatre company name] had any impact upon your perceptions of people with intellectual disabilities?

   **Prompts**  Activities  Living arrangements  Employment  Relationships  Expectations of achievement  Behaviour towards PwID  Everyday life
5. Why do you think [theatre company name] has had these impacts?
Appendix 24. Sources of support form for members with ID.

Thank you for talking to me today. If you feel you need further support after talking to me, then below is a list that might help.

If you have any problems or questions just about taking part in the research, you can contact me:

Danielle Dickinson (contact number removed for binding)

You can also speak to [removed for anonymity] at [theatre company name] or via phone: [removed for anonymity]

If you are worried about your own health or well-being: You could speak to someone in your family, a member of staff or your doctor.

Online support and general information available

Mencap
Website: https://www.mencap.org.uk
Telephone: 0808 808 1111

Foundation for People with Learning Disabilities
Website: http://www.learningdisabilities.org.uk/
Appendix 25. Sources of support form for significant others and community members.

Thank you for taking part in the study. If following the focus group today you feel you need further support, then below is a list that might help.

If you have any specific problems or questions that taking part in the research has raised, you can contact the research team:

Danielle Dickinson (contact number removed for binding)

You can also speak to [removed for anonymity] at [theatre company name] or via phone: [removed for anonymity]

If you are worried about your own health or well-being: You could contact your GP.

Online support and general information available

Mencap
Website: https://www.mencap.org.uk
Telephone: 0808 808 1111

Foundation for People with Learning Disabilities

Website: http://www.learningdisabilities.org.uk/
Appendix 26. Worked example of analysis.

<table>
<thead>
<tr>
<th>Descriptive codes</th>
<th>Transcript</th>
<th>Exploratory comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alphabet</td>
<td>Researcher: Ahh, brilliant. What, do you think [theatre company name] have any impact on your life?</td>
<td>Unique opportunity not available elsewhere?</td>
</tr>
<tr>
<td>TM13: Yes it has because I mean when I lived back in [location name] there was nothing like this back in [location name] and erm there’s nothing, I don’t know there’s anything like that back in [location name]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TM13: And I’m hoping to, not go back to live in [location name] but I’m hoping to go next, hopefully gonna go [location name] next, some through some next time, sometimes next time, I want, I was gonna see if someone to, if a, if a, someone could start up a [theatre company name] [location name]</td>
<td>Value of theatre company in life so want to start organisations in other places?</td>
<td></td>
</tr>
<tr>
<td>TM13: [or] something like that</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TM13: Because, ‘cos people round [location name] don’t have much to, sometimes don’t have much to do</td>
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<tr>
<td>TM13: And if, I think it’s best if they had like a [group name] and they had some other people to learn they could put on plays and they can come see and us they can, we go see them and things like that</td>
<td>Wanting other people to get a similar experience?</td>
<td></td>
</tr>
<tr>
<td>TM13: And I’ve also thought about it again erm because I’ve got family out</td>
<td>Networking? Making connections?</td>
<td></td>
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</tbody>
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<table>
<thead>
<tr>
<th>Descriptive codes</th>
<th>Transcript</th>
<th>Exploratory comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theatre company has impacted on life</td>
<td></td>
<td></td>
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<tr>
<td>Uniqueness of theatre company</td>
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<tr>
<td>Wanting to start similar organisations in other places</td>
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<tr>
<td>Something to do</td>
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<tr>
<td>Being occupied</td>
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<tr>
<td>Learning at the theatre company</td>
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<tr>
<td>Building relationships with other theatre companies</td>
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<tr>
<td>Setting up theatre companies globally</td>
<td></td>
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<tr>
<td>Helping others start their own theatre companies</td>
<td>there in [location name], [theatre company name] [location name] as well so I thought of [theatre company name] [location name], [theatre company name] [location name]</td>
<td></td>
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<tr>
<td>------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
<td></td>
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<tr>
<td>Researcher: Oh wow</td>
<td>Recognising what they have to offer? Modelling to others? Self-esteem?</td>
<td></td>
</tr>
<tr>
<td>TM13: So starting them off round there and then let someone take over but if they, if they still want any input, I still, they could still get in touch with me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Researcher: Yeah, ahh</td>
<td></td>
<td></td>
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<tr>
<td>TM13: [so]</td>
<td></td>
<td></td>
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<tr>
<td>Researcher: So you said that it has had an impact on your life</td>
<td></td>
<td></td>
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<tr>
<td>TM13: [it has] it has</td>
<td></td>
<td></td>
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<tr>
<td>Researcher: What…in</td>
<td></td>
<td></td>
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<tr>
<td>TM13: Erm</td>
<td></td>
<td></td>
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<tr>
<td>Researcher: Could you say a bit more about that</td>
<td></td>
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<tr>
<td>TM13: [I’d say] it’s erm, err it’s more like, I know their friends but it’s more like, it’s more like a family, it’s more like they’re your family</td>
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<tr>
<td>Making friends</td>
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<tr>
<td>Theatre company being a family</td>
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<tr>
<td>Everyone being friendly</td>
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<tr>
<td>Fondness of other members</td>
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<tr>
<td>Importance of facilitators</td>
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<tr>
<td>Making friends</td>
<td></td>
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<tr>
<td>Recognising what they have to offer? Modelling to others? Self-esteem?</td>
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<td></td>
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<tr>
<td>Dealing with adversity? Someone passing away</td>
<td></td>
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<tr>
<td>Theatre company being like a family</td>
<td>so many people really</td>
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<td>----------------------------------</td>
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<td></td>
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<tr>
<td>Researcher: Ahhh</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TM13: And it’s just like an added family really</td>
<td></td>
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<tr>
<td>Researcher: So something about coming to [theatre company name] has given you an added family</td>
<td></td>
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<tr>
<td>TM13: [oh coming, oh something, something] well yeah coming to [theatre company name]’s given me an added family but also erm I don’t like sitting round being bored</td>
<td></td>
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<tr>
<td>Sense of purpose?</td>
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<table>
<thead>
<tr>
<th>Something to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being occupied</td>
</tr>
<tr>
<td>Researcher: [oh]</td>
</tr>
<tr>
<td>TM13: I like doing something, I like being busy, and that’s why I like to work and also [theatre company name] and things like that</td>
</tr>
<tr>
<td>Sense of purpose?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Going to theatre company best thing done/value of it</th>
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</thead>
<tbody>
<tr>
<td>Researcher: [ahhh]</td>
</tr>
<tr>
<td>TM13: So I’m glad I’ve come to [theatre company name] because it’s best thing I ever did, come to this, from [location name] to here</td>
</tr>
<tr>
<td>Sense of purpose?</td>
</tr>
<tr>
<td>TM13: So since me dad passed away so yeah</td>
</tr>
<tr>
<td>Researcher: Ahhh. Are there any other ways you think [theatre company name]’s impacted on… apart from sort of having that extended family and having something to do so you’re not bored, are there any other things that you think are important?</td>
</tr>
<tr>
<td>Importance of theatre company when not from the area?</td>
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<table>
<thead>
<tr>
<th>Others enjoying the shows</th>
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<tbody>
<tr>
<td>Positive emotions about audience enjoying it</td>
</tr>
<tr>
<td>TM13: [but] erm yes there is lot of things that are important, I mean the plays we put and we have good audiences and that’s brill, it’s, it’s brilliant ‘cos the plays we put on to see the audiences faces and see the, see a packed audience and play in front of packed audience, that is</td>
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<tr>
<td>Positive emotions about audience enjoying it</td>
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<td>---------------------------------------------</td>
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<tr>
<td>brilliant</td>
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Helping other members

TM13: [yes] yes
Researcher: Okay

Researcher: Okay

TM13: And also helping with the, also it’s nice to help with the junior group as well [group name]

TM13: I’ve seen them, and now I’ve seen some of them who’ve come here, and they’ve gone to the bigger group and things like that

TM13: People like [member name], erm [member name] and all that business they started from [junior group name] and now they come to the bigger group

Researcher: So what’s nice about helping, you said it was nice to help, what’s nice about it?

TM13: [it’s nice to help] because erm it’s nice to offer your, their, your experience to them ‘cos when they start a younger age, it’s, they, it’s a step up, it’s a stepping stone from, [junior group name] is a stepping stone from [junior group name] so when they get too old to do [junior group name]

TM13: Then they can move up to the bigger group and things like that

TM13: [it was nice to be able to] it was nice it was when I do when I was

Feeling like part of other peoples’ journey because helped?
Accomplishment/achievement?

Being wise?

Something to offer others? Feeling valuable to other people?
<table>
<thead>
<tr>
<th>Positive emotions about helping</th>
<th>There it was nice to help with that</th>
<th>Researcher: Ahhh, brilliant so something about helping with that stepping stone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>TM13: [yes]</td>
</tr>
<tr>
<td>Others coming to watch</td>
<td></td>
<td>Researcher: Okay and you know you said about when audiences come and watch and it’s sort of packed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TM13: Because also erm I get, I…used to have some fr, I used to have some friends and me family used to come from [location name] to come and see me as well</td>
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<tr>
<td></td>
<td></td>
<td>Researcher: [ahhh]</td>
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<tr>
<td></td>
<td></td>
<td>TM13: So they used to come see the shows as well and my sister does and things like that</td>
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<td></td>
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<td>Researcher: [ahhh]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TM13: ‘Cos she lives in [location name] still so I've got family in [location name] so that’s not too bad</td>
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<tr>
<td></td>
<td></td>
<td>Researcher: [yeah] what do they say about the shows?</td>
</tr>
<tr>
<td>Audiences enjoying the shows</td>
<td></td>
<td>TM13: They love them, they all, they love them they every one we did they loved them</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Researcher: [ahhh]</td>
</tr>
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</table>
Appendix 27. Epistemological statement.

Epistemology refers to what is knowable, and how you can obtain that which is knowable (Willig, 2013). Epistemology guides research at numerous levels, and this statement seeks to outline the epistemological stance underpinning the empirical paper of this portfolio thesis.

There are various epistemological positions one can adopt in approaching research, which will in turn affect methodological decisions or ‘research action’ (Carter & Little, 2007). At one extreme, positivist and realist epistemologies suggest that knowledge is objective and exists in the world, and we can, and want to, discover the ‘truth’ of something through research (Braun & Clarke, 2006; Willig, 2008). This position did not fit with the current study, as an interest in people’s experiences of involvement in the theatre company did not give a variable that could be objectively measured. Constructionist epistemologies adopt an opposing view, suggesting there is no external truth, and instead, language is used as a mechanism to construct our realities. Therefore, research from such perspectives is more concerned with how people have come to construct or understand something in a certain way, based upon their context (Willig, 2013). Similarly, this does not fit with the current research, as an interest in hearing people’s experiences of the theatre company was giving their reality some weight or ‘truth’, and the focus was less upon how they had come to construct their reality in that way.

Between the two lie phenomenological epistemologies, focusing on peoples’ experiences and really wanting to understand something from participants’ perspectives (Willig, 2008). Thus, what is important is that people speak about what is a reality for them, rather than the external validity or objective truth of their accounts (Willig, 2008).
This appeared to fit with the current research, as the researcher wanted to know about people’s experiences of the theatre company. Moreover, this research was conducted as part of a training programme in Clinical Psychology. Listening to people’s experiences and their unique perspective is a fundamental part of this profession, so a phenomenological epistemology also fits with the researcher’s values more broadly. Within phenomenological epistemologies, a descriptive phenomenology stays close to the data, and wants to know about peoples’ experiences as they share them, rather than bringing meanings from external sources to their experiences (Willig, 2008). However, an interpretative phenomenology goes beyond what the person says to understand the meaning of this relative to broader social, cultural and theoretical concepts (Willig, 2008). Although the researcher was interested in how the results of the study fit within a broader context, this was more related to the implications of the results, rather than being used to guide the analysis itself. Therefore, staying as close to the participants’ experiences as possible appeared to fit most closely with the research aims, and therefore, positioned the researcher within a descriptive phenomenological epistemology. However, within this, it is acknowledged that qualitative research always involves some level of interpretation, with researchers bringing their inescapable beliefs and values to research, which inevitably affects the research process in various ways (Elliott, Fischer & Rennie, 1999).

Once this approach to knowledge was established, how to gain knowledge of people’s experiences of the theatre company was next considered. As quantitative research fits with more positivist epistemologies and involves measuring variables predefined by the researcher (Willig, 2008), this did not fit with wanting to know about participants’ experiences, so a qualitative methodology appeared more appropriate. Discourse analysis fits with more constructionist epistemologies, as such analyses focus more
upon how people have articulated something rather than the content of what they have said (Willig, 2013), and so this was discounted due to adopting a more phenomenological stance. Interpretative phenomenological analysis fits with a phenomenological stance, but involves making meaning from peoples’ experiences based upon their context (Smith, Flowers & Larkin, 2009). This again did not appear consistent with the research aims, with less focus on ‘meaning-making’. Grounded theory and narrative analysis were also considered, as these methods are not tied to particular epistemologies (Willig, 2013). However, these methods were again discounted, as the research was not about developing a theory of how a concept worked or how people storied their experiences of the theatre company, respectively. Thematic analysis is another qualitative method not positioned within a particular epistemological stance (Braun & Clarke, 2006). This method appeared most fitting with the research wanting to hear about people’s experiences of the theatre company, and believing this was a ‘true’ reality for participants. Moreover, this method also enabled the researcher to stay with participants’ accounts, rather than bringing external information to make meaning of their experiences, consistent with a descriptive phenomenological stance. Thematic analysis can also be used to see how a group conceptualise a phenomenon, and look for variations in conceptualisations across groups (Joffe, 2012). This was also fitting with the multiple participant groups within the research design.

Consistent with a descriptive phenomenological epistemology, an inductive or ‘bottom-up’ approach to thematic analysis was adopted, focusing on what comes from the data rather than coding for what previous research has already shown may be important, as when adopting a deductive approach (Braun & Clarke, 2006). As this was a novel area of research, this approach appeared more appropriate, with the literature not pointing to specific concepts which would be important to code for in considering people’s
experiences of the theatre company, particularly for significant others and community members. This is not to say that the researcher had no understanding of the literature around the impacts of arts projects for people with intellectual disabilities through undertaking background research for the study, but this was not used to guide analysis. Linked to this, the thematic analysis was more semantic than latent, looking at explicit meanings rather than considering what shapes the semantic content respectively, as the latter again comes from a more constructionist paradigm (Braun & Clarke, 2006). However, again, not only the semantic content of the data is presented, as the themes are contextualised more broadly and patterns across the data considered. As thematic analysis has moved beyond its roots in conversation analysis involving counting the number of times things are mentioned to develop themes (Willig, 2008), themes in this analysis were classified based on whether they said something meaningful about participants’ experiences overall, rather than the number of times or number of participants that mentioned something (Smith, 2011).

A final point is the professional orientation and values of the researcher that will have inevitably affected the approach adopted. Thus, the research is influenced by the researcher’s passion for and interest in community psychology approaches, highlighting the significance of the ‘social’ rather than the ‘individual’ in distress, and the importance of empowering marginalised groups to produce change (Kagan & Burton, 2005). The theatre company has unavoidably been perceived through this lens. Moreover, the researcher is also interested in Narrative Therapy, highlighting the alternative stories that people can generate about themselves to alleviate distress (White, 2007). Thus, in the context of PwID, this would involve generating alternative stories around inclusion, empowerment and strength, rather than deficit and oppression which is usually the dominant story in the lives of PwID (McParland, 2015). Finally, the
research has also been influenced by a radical humanist paradigm. This approach
criticises the status quo, and emphasises the importance of overcoming the restrictions
society places upon human development (Burrell & Morgan, 1979). In this context, the
researcher’s belief is that the culture around ID can create barriers for people and does
not allow them to have valued identities (Goodley & Lawthom, 2005). These ideas have
been influential in the research and thus, the researcher believes in allowing PwID to
realise their full potential through overcoming the restrictions placed on individuals
with ID in society (Burrell & Morgan, 1979).

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Open University Press


Appendix 28. Reflective statement.

Producing this thesis has been both a challenging and enlightening journey, questioning my own values and assumptions along the way. I hope this will give you some insight into the things I have learnt over the past three years, and what I will take forwards from the project into the future.

Empirical paper

Choosing a topic

I heard about Community Psychology early into the course, and these theories put into words something I had felt for a long time – that I’m not sure how well I would be doing if I was living in a similar situation to some of the people I worked with. I wondered if I could make this into a research idea and took to the Internet, finding various community projects far and wide, from a hip-hop music company for disadvantaged young people in London, to a nightclub for people with intellectual disabilities (PwID) in Hull. I then stumbled across Forum Theatre and its use with people that were homeless. The premise was that as audience members, they could enter the theatre performance and change what happened next, with the idea that this could empower them to change the story of their lives. I found this inspiring and thought I will set up my own Forum Theatre production and change people’s lives!!!!! After some thoughtful staff reining in the overly ambitious ideas of a first year trainee, a theatre company for PwID locally was mentioned, and I thought this may be a little more realistic.

Choosing a project with PwID came as a surprise. Before the course, I worked in an inpatient hospital for PwID, and there was a sense of hopelessness and acceptance that
things would not improve for the clients there. As I wanted to make a difference to people’s lives, this wasn’t an area of clinical work that appealed. However, a conversation with Dr Chrissie Blackburn around my values more broadly helped me consider how a project with PwID might fit better than I thought. We spoke about justice and fairness being things that really matter to me, and I realised that I saw the treatment of PwID as unjust and unfair. With the promise that Community Psychology approaches offered ways to challenge the societal position of disempowered groups, a project with PwID seemed encouraging.

**Designing the project**

Community Psychology and theories of systems also influenced the research design, realising that if I truly believed in the ‘social’ in distress, I would need to look beyond the impact of the theatre company at an individual level. Drawing how I saw the participant groups with Dr Lesley Glover was a really helpful way of conceptualising the multiple perspectives, and showed me the power of drawing things that are difficult to put into words, something I also applied in later stages of the project. When designing the research, I was overwhelmed by the enthusiasm from the theatre company. Having people as invested in the research as I was has truly made every aspect of the process easier, and I would recommend finding ‘allies’ for anyone undertaking research. However, this also came with an added pressure. Seeing how much the research meant to the theatre company made me realise how much I wanted to do a ‘good job’. Having one organisation I was recruiting from seemed to make this even more real, and somehow sharing their collective voice in the way they wanted seemed more of an onerous task than if I had recruited unconnected participants from around the country.
**Obtaining ethical approval**

Applying for ethics was my first warning sign that I had maybe bitten off a little more than I could chew, as having three participant groups meant three times the work! I was also surprised by the ethics committee’s response to doing research with PwID. They wanted more safeguards in place for their involvement compared to the significant others and community members I was recruiting. Although understandable, I couldn’t help feeling the sense of injustice rise again that the PwID were not being seen through the same lens as the other adults participating in my research. After overcoming these initial difficult feelings, I realised the ethics committee wanted to ensure I would not be causing harm through my research, which is not something I wanted to do either. On reflection, I think their feedback helped me consider aspects of the project more thoughtfully and thoroughly, asked questions of the project I had not asked myself, and ultimately, improved the quality of my research.

**Recruitment and data collection**

Recruitment placed me in the opposite position to many of my peer researchers - their anxieties were around getting enough participants, whereas mine were around having too many! But I was overjoyed by all of the interest in the research, and was able to complete the interviews and focus groups in a short time. However, as the interviews progressed, a sense of confusion built that all of the PwID I interviewed seemed happy, and did not only talk about the oppression and exclusion they experienced, but also spoke of joy and positivity. At this point, I thought it was time to reflect upon my own perceptions and understandings of intellectual disabilities, before I considered those of my participants. I pondered how I approached the project feeling pity towards PwID – they did not want an intellectual disability, they felt angry at the world for it, and quite rightly so! My participants showed me I could not be further from the truth. They were
not angry or bitter; they were more than happy, and for some people, having an intellectual disability didn’t seem to bother them at all. I also noticed how people just spoke about normal life –relationships, emotions, challenges…it wasn’t all about the tragedy of having an intellectual disability as I was expecting. Seeing this humanness during the interviews helped me realise that my previous perceptions didn’t allow me to see this common humanity at all. I questioned why I might have come to see PwID in this way, and it struck me that I had only ever known PwID in a clinical capacity, either as a support worker or through my final year placement. Thus, this challenged my own perceptions that the lives of PwID did not always have to involve distress.

Before embarking on the project, I also had a view that PwID would be constantly fighting for their independence. However, it seemed many participants had a balanced view of their strengths and things they needed more help with. Seeing this made me realise that ignoring the reality of having an intellectual disability was perhaps as ignorant as seeing this as the only thing that defines a person. Furthermore, I also faced an ethical dilemma around asking participants about the perceptions others held of them, if this would bring something into their awareness that perhaps hadn’t bothered them before. Accompanied by feeling like the participants wanted me to take the lead within the interviews, maybe because this is what they were used to, I wasn’t sure how to proceed. Supervision enabled me to use the interview schedules flexibly rather than following a list of questions rigidly, and I adopted the approach of going with what the participants said, and only picking up on others perceptions if the participant led the conversation that way or it felt appropriate in the context.

Furthermore, the focus groups really emphasised the importance of having multiple perspectives on the theatre company, and I could see the value of this already. However,
I was struck by some of the language used in the focus groups, including describing people as “suffering” from an intellectual disability, and the term “handicapped”. Prior to the research, I was heavily caught up in the use of language, the position it put those being described into, and also what it said about those doing the describing. However, this challenged my ideas around the use of language as although they were using terms I felt uncomfortable with, their perceptions of and attitudes towards PwID were filled with great compassion, kindness and joy, and I realised that this was much more important than the language they used.

**Analysis**

Despite transcription and coding being time consuming with the amount of data, this was the most enjoyable part of the project. I could hear the participants’ voices through the transcripts, and at times, felt powerful, overwhelming emotions through knowing how much their stories meant to them, and how I had been entrusted with something so precious. There was also an interface during analysis with my clinical placements. Thus, my epistemological stance and method of analysis focused on staying with people’s descriptions of their experiences and not bringing interpretations to the data. However, I was working from a psychoanalytic perspective on placement, involving looking beyond the content of what people have said, and offering interpretations relative to the unconscious. Thus, it felt like I was often switching between research and clinical hats, accompanied by another hat switch when on placement with PwID. In hindsight, I am not sure how well this switching worked, and I think my analysis was inescapably influenced by the new understandings a psychotherapy placement bought. In the future, I would consider this interface between clinical work and research in greater depth, as I feel consistency between the two may be more important than I initially anticipated.
Additionally, developing themes also provided useful learning points. After agonising over where some codes might fit, I decided a new approach was necessary if I was ever going to complete my research on time! If within a few minutes I hadn’t decided where a code might go, it went into the “not sure where they go” theme. As someone who likes to get things right, this initially felt uncomfortable (along with knowing that there was never going to be a ‘right’!). However, I soon realised the “not sure where they go” pile was much more manageable when you had some initial ideas about where other codes might go. On reflection, I adopted a similar approach when coding, as if I couldn’t think of a snappy phrase or few words to describe what participants were talking about, I would call the code “something like…” and write all of the words that were spinning around in my mind. I think this approach allowed me to move away from wanting everything to be ‘perfect’, helping me to continue progressing with the research, and sticking with this ‘not knowing’ is something I will definitely take forwards into future projects. Moreover, I went back to my earlier habits of drawing how I saw the codes fitting together in my mind, and this was another invaluable strategy in developing themes.

Additionally, I found not being able to escape the codes or themes from different data sets challenging. For example, if I saw friendships as ‘connections’ in one data set, it was hard not to see this in the same way for another. Although there were times I felt like I wanted to wipe my mind of the previous analysis or get someone else to make my themes for me, this demonstrated how immersed I had become in the data, and reflecting upon this process and its impact will hopefully add to the rigour of the research.
Writing up

Choosing a Community Psychology journal appeared appropriate, with the underpinning theories of the project and the impact I wanted it to have going beyond PwID. Deciding how to write up three sets of results simultaneously was difficult initially, but seeing the themes converge across the groups left me feeling it was repetitive and unnecessary to separate the groups, and that bearing witness to change in others felt like a really powerful and important process to emphasise. Trialling different ways of presenting the results was the most helpful way of discovering which way of writing up worked best. Furthermore, I struggled with feeling attached to participants’ quotes, and the preciousness of what I was entrusted with again resurfaced. After realising the first theme I had written was over 2000 words, I realised this was not feasible for a concise report. A peer researcher reading over my results was extremely helpful within this process. They told me, as an outsider who was not emotionally invested in the data, which part of a quote was necessary for them to get from it what they needed. This advice was exceptionally helpful; along with Dr Lesley Glover informing me that qualitative analysis is about trying to tell the story of the data that means the person doesn’t have to read all of the transcripts themselves. This is something that will stay with me through future research, as it eased my feeling of “doing it wrong” - if I was trying to tell the story of the data to the best of my ability, I couldn’t be going that wrong!

Moreover, I considered including a drawing or diagram of how I conceptualised my themes in the final write up, as I had found this such a helpful strategy throughout. However, I think diagrams during many stages of the research helped me clarify things in mind, and therefore, seemed easier to put into words when writing up, and so I chose not to include a diagram – I’m still not sure if this was the right decision!
Bringing the thesis together as a coherent whole was my final hurdle. As I wrote sections at different points, it felt quite clunky and disjointed, and I struggled with making it flow initially. I also felt panicked that I wasn’t sure I had answered the research questions, but writing the discussion seemed to help bring the research together as a coherent article, and there was a sense that the whole was greater than the sum of its parts.

The process as a whole
Overall, the project has given me an insight into my own tendency towards “big ideas”, and how I can often make things hard for myself. I have reflected upon the toll this may take over time, and although I don’t think the project has fully steered me away from doing things the hard way, I hope to continue developing this insight. It has also challenged my own perceptions of PwID, just as I was hoping the theatre company would do for other people. This is something I did not anticipate, but I would give deeper consideration to my own perceptions in a given area before embarking upon future research. Moreover, I think this change in perception will have wider benefits, such as when working with PwID professionally. The project has also given me a new understanding of what it is to be scientific, rigorous, and transparent in the context of qualitative research. Additionally, the research has shown me that I am a visual thinker, and I will continue drawing what I don’t have the words for – this is something I have also recently bought into my client work. To conclude, I have often felt like an outsider for not seeing the value of individual therapy in light of a social context that I think would make it impossible for someone to be ‘well’. At points, I have nearly given up on changing the world, but this project has reignited my hope not to give up just yet. I
think Margaret Mead’s quote sums up this philosophy wonderfully, and summarises the final stopping point on this journey for me:

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.”

**Systematic Literature Review**

The topic for my literature review came easily. Since starting on the course, I have been perplexed by the limited discussion around what the “intervention” part of therapy entails, and been mystified by what therapists actually do in the room for an hour. This perhaps arises from my own impatience around wanting to get things done, so choosing a question around the ‘doing’ seemed apt in this context.

Finalising a search strategy and using the electronic databases was an initial challenge, and realising how much a punctuation mark could completely change your search results was a little anxiety provoking to say the least! However, I have learnt the value of these databases, and have also since incorporated them into my clinical work. I have also realised the importance of logging searches and results, as a much easier way to keep track of a review, both valuable learning points for future research.

Finding similar reviews was initially daunting and made me reconsider the review as a whole, but reassuring conversations and advice from Dr Nick Hutchinson helped me delineate my review as a novel piece of research. I also found data extraction challenging, due to the methodological and design limitations outlined. However, this perspective as a reader and also using the quality assessment tools were extremely helpful in writing my empirical paper. Thus, I was able to consider what may be easiest
to understand and most clear from a reader’s perspective, rather than trying to cram in every aspect of the project from the past three years.

Writing up the article outlined the value of such reviews in practice. Hence, I again positioned myself as a reader, considering how much easier it would be to read this condensed version rather than reading the 19 papers individually. Thus, choosing a widely known journal for intellectual disabilities seemed appropriate if I wanted to ensure the article reached the relevant readership. Although I would not undertake another review lightly, I can see the value of such research, and will continue to draw on the findings of systematic literature reviews within clinical practice.