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**Changes in understandings and perceptions of individuals, significant others and
community supporters involved in a theatre company for adults with intellectual
disabilities**

Running Title: Changing perceptions of intellectual disabilities

Key words: Intellectual Disabilities; Perceptions; Arts; Theatre; Community Psychology

Abstract

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

Methods: The impacts of a theatre company on understandings and perceptions of intellectual disabilities from multiple perspectives were explored. Interviews with members with intellectual disabilities (n=14), and focus groups with significant people in their lives (n=11) and community supporters (n=10) 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 parts of life they are often excluded from, and enabled growth for all participants, leading to a desire to extend the theatre company's ethos elsewhere.

Conclusions: The importance of such organisations to improve perceptions of people with intellectual disabilities is emphasised.

Introduction

People with intellectual disabilities 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 people with intellectual disabilities are improving (e.g. Ouellette-Kuntz, Burge, Brown & Arsenault, 2009), others highlight the bullying and hostility people with intellectual disabilities face (Flynn & Russell, 2005; Scior, 2003; Scior & Werner, 2015). Research conducted with people with intellectual disabilities shows that many experience social exclusion and marginalisation relative to core aspects of society including education, employment, opportunities for community participation, and development of relationships and friendships (Abbott & McConkey, 2006; Nicholson & Cooper, 2013; Welsby & Horsfall, 2011), as well as discrimination and victimisation within their communities (Beadle-Brown et al., 2014). Furthermore, misunderstandings such as an intellectual disability being a mental illness still exist within society, and the public continue to want to maintain their distance from people with intellectual disabilities (Mencap, 2016). Overall, it appears people with intellectual disabilities are perceived negatively by society and remain isolated.

This negativity is not just limited to wider society. Research involving healthcare staff has shown that some professionals view working with people with intellectual disabilities as undesirable, and perceive people with intellectual disabilities as a homogenous group that can be aggressive and difficult to engage (Kordoutis, Kolaitis, Perakis, Papanikolopoulou & Tsiantis, 1995; Lewis & Stenfert-Kroese, 2010). Additionally, research exploring the perceptions of family members of people with intellectual disabilities highlights how parents can become overprotective, and express concerns about their children's independence, employability and opportunity for family life in the future (Chandramuki, Shastry & Vranda, 2012; Heiman, 2002).

These negative perceptions are thought to create a self-fulfilling prophecy for people with intellectual disabilities. Thus, they internalise the expectations of others (Scior, 2003), and experience low self-esteem, worth and confidence, resulting from feeling rejected, devalued and insignificant (Goodley, 2001; Paterson, McKenzie & Lindsay, 2012). These perceptions can also negatively impact upon the emotional wellbeing of people with intellectual disabilities, with wellbeing defined in this study as generally feeling good about oneself and being able to cope with one's own emotions (Eaude, 2009). Thus, people with intellectual disabilities often experience depression, anxiety, anger, and shame, following striving for acceptance and status in communities that are stigmatising and isolating (Dagnan & Waring, 2004; Jahoda, Wilson, Stalker & Cairney, 2010).

More recently, the impact of society's negative perceptions upon people with intellectual disabilities has been acknowledged, and improving society's perceptions has been highlighted as the fertile ground for change (Dudley-Marling, 2004). Interventions to improve perceptions of adults with intellectual disabilities include integrative programmes such as unified sports (Ozer et al, 2011; Sullivan & Glidden, 2014), adventure activities (Anderson, Schleien, McAvoy, Lais & Seligmann, 1997), and programmes to promote friendships amongst people with and without intellectual disabilities (Hardman & Clark, 2006). Moreover, interventions to challenge negative perceptions of people with intellectual disabilities have been implemented, including educational programmes involving face-to-face contact with people with intellectual disabilities (e.g. Bailey, Barr & Bunting, 2001); indirect contact through media portrayal (e.g. Walker & Scior, 2013); and interventions to change staff perceptions (e.g. Tsiantis, Diareme & Kolaitis, 2000). These later approaches involving stakeholders in wider 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 society's perceptions of people with intellectual disabilities (Cameron, 2007). Capability Theory, which suggests society generally focusses on what people with disabilities cannot do, rather than what they can do (Goodley, 2001; Vorhaus, 2015) and Community Development Theory, which emphasises how participation is key in challenging disempowerment (Sloman, 2011), offer a conceptual understanding of how disability arts can have a positive impact on society, by providing an opportunity for people with intellectual disabilities to show their otherwise hidden abilities and to be an active participant in the wider community. Generally, art, multimedia and drama groups have shown many individual benefits for people with intellectual disabilities including personal growth, developing social bonds and improved wellbeing (Matarosso, 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 people with intellectual disabilities (Cameron, 2007; Roulstone, 2010; Vorhaus, 2015). People with intellectual disabilities report numerous benefits of being involved in such theatre companies including improved self-confidence and self-identity (Hall, 2011).

However, limited research has considered the impact of such theatre companies on families of people with intellectual disabilities or on wider society, but the small literature base that exists suggests both groups are surprised by what people with intellectual disabilities can do (Hargrave, 2010; Vorhaus, 2015). More research considering the impacts of theatre on stakeholders in wider levels of context is needed (e.g. Faigin & Stein, 2010); research that goes beyond the impacts of one performance at a specific point

in time is also lacking. Such research may suggest alternative approaches to changing perceptions of people with intellectual disabilities amongst family members and in wider society. Consequently, if such perceptions negatively impact upon how people with intellectual disabilities feel about and view themselves, this may also suggest alternative ways to generate more positive self-identities of people with intellectual disabilities.

Research Questions

The study considered changes in understandings and perceptions of intellectual disabilities from the perspectives of various stakeholders involved in an established theatre company, namely people with intellectual disabilities themselves, families and carers termed ‘significant others’, and supporters from the community. The following research questions were proposed:

- How do people with intellectual disabilities, significant others and community supporters make sense of their involvement in a theatre company?
- How does this involvement impact upon how people with intellectual disabilities 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 people with intellectual disabilities amongst significant others and community supporters, and on how they live their lives?

Method

Design

A qualitative design using semi-structured interviews with members of the theatre company who have intellectual disabilities, and focus groups with significant others and community supporters was employed to explore the impacts of the theatre company and perception change around intellectual disabilities from multiple perspectives.

The researcher met with a consultation group including adults with intellectual disabilities and significant others involved in the theatre company early in the development of the study to inform the design. The group provided feedback on the proposed aims and research questions, and possible methods of data collection; they also checked the suitability of information sheets, consent forms and research procedures. The group proposed that interviews, rather than focus groups, should be carried out with members to give people with intellectual disabilities an opportunity to share their individual perspectives. The consultation group also reviewed the semi-structured interview schedules and offered suggestions for improvement.

Recruitment

Participants were recruited through a theatre company for people with intellectual disabilities in Yorkshire with approximately 150 members with intellectual disabilities. Three groups of participants were recruited, members of the company who have intellectual disabilities, significant others in members' lives, and supporters from the community. Participants were recruited through flyers placed around the company building, given to potential participants at events, 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.

Inclusion Criteria

Members of the 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 people with intellectual disabilities.
- Expressed an interest in sharing their views about the theatre company.
- Were able to communicate verbally on a 1-1 basis.
- Were members of the theatre company for any length of time.
- Had the capacity to consent to participate. In accordance with the Mental Capacity Act (Department of Health, 2005), it was assumed individuals had capacity unless it was apparent they could not fulfil the core principles relating to understanding and retention of information, and ability to communicate a decision.

Significant others and community supporters were eligible to participate if they expressed an interest in sharing their views about the theatre company. Significant others could be anyone with significant involvement in a member's life, including family members, carers and residential staff, and volunteers at the organisation, and were included regardless of whether the person they cared about was involved in the interviews. There were no specific inclusion criteria for community supporters, but some level of involvement was assumed due to them being known to the company.

Participants

Theatre Members

The first author met with 23 theatre members to discuss the information sheet face-to-face and spoke to one member via telephone. One person could not participate, as they did not have an intellectual disability; 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 to participate in the study. Overall, 14 (8 males, 6 females) members participated in individual interviews. 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 at the theatre company per week (range= 2-5). These groups, run by professional artists, involve members engaging in various singing, music, dance, film-making, stage and drama activities that promote community participation and involvement, and prepare members for performances at local venues. Demographic information is detailed in Table 1.

Significant others

The first author contacted 23 significant people in members' lives via telephone and e-mail. One person did not want to participate, seven people could not attend on the focus group dates, 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. Therefore, 11 significant others (4 males, 7 females) participated overall, six participants in the first focus group, and five in the second. Ages ranged from 38-67 years (mean= 56.5 years).

Six significant others were parents, two were carers and three were support workers. Three significant others were also volunteers. The amount of time their child or person they care for had been a member of the theatre company varied from one year to over nine years. Demographic information is detailed in Table 2.

Community supporters

The first author contacted 11 supporters from the community via telephone and e-mail regarding the research. One person could not attend on the focus group dates, with 10 community supporters (2 males, 8 females) participating overall, seven in the first focus group, and three in the second. Ages ranged from 30-83 years (mean= 62.8 years). Community supporters had been involved with the theatre company from one year to over nine years. The nature of this involvement differed, but all community supporters identified attending company performances (up to 6 events per year). Demographic information is detailed in Table 3.

Ethical Approval

Ethical approval was attained from a local University Research Ethics Committee. At the beginning of each interview and focus group, to remind participants fully about what the study was about and to ensure participants were providing informed consent to participate, the researcher read through the research information sheet in the presence of the participant (s). Written consent was then obtained from all participants prior to the interview/focus group. Three theatre members could not read and, therefore, were unable to read through the consent form. Thus, an independent person was present whilst the researcher accurately read the consent form to the participant; the form was then signed by the participant and countersigned by the witnessing independent person.

Data collection

Individual interviews were carried out with theatre members, and significant others and community supporters took part in separate focus groups. Interviews and focus groups were guided by semi-structured interview schedules (Smith, Flowers & Larkin, 2009), developed through reviewing relevant literature, and discussions with a consultation group. The rationale for using both individual interviews and focus groups to collect data was that the researcher was keen to gain multiple perspectives on the research topic through methodological triangulation, empowering people with intellectual disabilities to share their own individual viewpoints whilst encouraging significant others and community supporters to share and reflect upon their understandings and perceptions in conversation with each other. All interviews and focus groups were conducted face-to-face and were audio-recorded and transcribed. Interviews lasted between 11 and 60 minutes (mean= 45 minutes). The significant others' focus groups lasted 63 and 76 minutes, and the community supporters' focus groups lasted 56 and 31 minutes.

Data analysis

Inductive thematic analysis was used to analyse the interviews and focus groups, as thematic analysis can identify patterns within data sets, and can be used to highlight variations in conceptualisations of phenomenon across and between groups (Braun & Clarke, 2006; Joffe, 2012). The data sets were initially analysed separately, following Braun and Clarke's (2006) guide for conducting thematic analysis. This involved the following steps: 1) Data transcription; 2) Thorough review and reading of the transcripts with the researcher noting points of interest across the transcripts; 3) Generation of initial thematic codes; 4) Initial codes were searched for across each data set, and collated into broader themes and subthemes; 5) Coded extracts within each theme were re-read to see

if they formed a pattern consistent across the whole data set. Reorganisations and movement between themes were made as necessary.

At this stage, the authors noticed a number of similarities in the themes and subthemes identified from the separate analyses of the three data sets. For example, theatre members discussed changes in themselves and their lives through being part of the theatre company, and significant others and community supporters discussed noticing these same changes in theatre members. To avoid repetitiveness, the themes were grouped across the three data sets.

Quality

During analysis, numerous measures were taken to ensure rigour and transparency associated with high quality qualitative research (Elliott, Fischer & Rennie, 1999). For example, to ensure credibility and trustworthiness of the themes generated through the analysis, once the researcher (first author) had generated codes and themes across the data sets, these were reviewed and checked by the researcher through discussion of excerpts from transcripts and the identified codes and themes with peer researchers in a qualitative research group. In addition, the second author independently read through a selection of individual interview transcripts, and the focus group transcripts, noting points of interest, which were then compared with the first authors' notes and initial codes during research discussions. Finally, the overarching themes identified by the first author across all participant groups were discussed and reviewed with the second author to ensure the integrity and trustworthiness of the final set of themes and subthemes. Elliott et al. (1999) state that it is good practice for qualitative researchers to reflect upon and *own one's own perspective* – their values, beliefs and assumptions - about research and the topic area, and the roles these might play in the search for meaning in the research data. The

researcher was alert to her own perspective and kept a reflective diary to monitor her own beliefs and assumptions about research, epistemology and the role of the researcher in the research process throughout the duration of the project.

Results

Four superordinate and nine subordinate themes were identified across the data sets (Table 4). The first and second superordinate themes relate to impacts of the theatre company on members with intellectual disabilities, namely connecting with others and experiencing parts of life they are often excluded from due to have an intellectual disability. These impacts were noticed by theatre members themselves, and also by significant others and community supporters. The third and fourth superordinate themes relate to how the theatre company has impacted upon all participant groups, namely through them growing as people through their involvement, and the theatre company being a preferred alternative to services usually offered to people with intellectual disabilities.

1. Connections

Participants discussed the social and community links members made through the theatre company.

1.1. Bonds with other members

Members discussed “*making loads of new friends*” (Mary – theatre member) 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” (Simon – theatre member)

Significant others 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” (Rita – significant other)

Members also emphasised the importance of everyone having intellectual disabilities in developing social bonds:

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

Significant others also echoed the importance of members all having intellectual disabilities:

“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” (Julie – significant other)

Members described their bonds going beyond friendship, describing the theatre company as a *“second family”* (Alice – theatre member). Significant others and community supporters also saw the bonds between members as like family:

“it’s just one big family” (Cathy – significant other)

“they’re like a little family” (Betty – community supporter)

Members discussed the importance of a helping aspect to their relationships with other members:

“I help people who aren’t as able as me” (Helena – theatre member)

Furthermore, significant others witnessed these helping relationships:

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

Community supporters could also relate to this from watching performances:

“they look after one another” (Victoria – community supporter)

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” (Frank – theatre member)

Moreover, significant others described how experiencing relationships *“brings another level of understanding”* (Tina – significant other) for their loved ones.

1.2. Community links

The theatre company also helped members develop 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” (Dave – theatre member)

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

“they don’t get stared at or talked about” (Cathy – significant other)

Community supporters 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” (Betty – community supporter)

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” (Billy – theatre member)

Significant others 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”* (Cathy – significant other)

2. *Experiencing parts of life they are often excluded from*

The theatre company enabled members to experience parts of life they are often excluded from, as at the theatre company, they are not treated as a person with a disability in need of sheltering.

Members described being challenged at the theatre company, describing the “*complicated*” (Tony – theatre member) and “*hard stuff*” (Helena – theatre member) they do, and wondering, “*how am I meant to do that?*” (Simon – theatre member). Members also discussed aspects of the theatre company they dislike including being “*bored*” (Alice – theatre member) and “*people winding you up*” (Helena – theatre member). However, one member articulated the importance of exposing people with intellectual disabilities 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” (Ben – theatre member)

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*” (George – theatre member) and the slow-pace of rehearsals; “*I know you have to stop and start but just makes it perfect*” (Helena – theatre member).

Significant others also discussed the importance of their loved ones being “*pushed to do things*” (Rita – significant other):

“It’d be wrong to say that no pressure’s put on them because believe me pressure is put on them....and it’s not a bad thing, you need rules in life don’t ya” (Julie – significant other)

Significant others described challenges in relationships members experience at the theatre company including *“fallouts”* (Julie – significant other), but how this is just *“human nature”* (Brian – significant other), emphasising that difficult experiences are part of everyday life. Moreover, community supporters described seeing members challenged by facilitators, and their reaction to this:

“they don’t accept second best, that surprised me” (Margaret – community supporter)

There was also a sense that being involved in the theatre company helped members see themselves as ‘normal’:

“we’re normal human beings like everybody else” (Dave – theatre member)

Significant others also expressed the importance of the theatre company showing members that their disabilities do not matter:

“nobody has a disability they all have an ability...at a different level” (Julie – significant other)

3. People growing as people

Furthermore, all participant groups identified that they had grown as people through involvement in the theatre company.

3.1. Purpose and achievement

The theatre company gave members a sense of purpose, with members suggesting they would “*be at a loose end*” (Frank – theatre member) without it, and it being “*nice to know that you live to do something*” (George – theatre member). Significant others also described how their loved ones “*wouldn’t be motivated*” (Cathy – significant other) without the theatre company. Additionally, having a purpose enabled members to achieve and identify their strengths. One member described conquering nervousness around performing:

“*‘Cos I were literally sick with panic...and by Saturday, I absolutely pulled through it and I did absolutely brilliant*” (Katie – theatre member)

Achievement linked to pride for members, feeling “*honoured*” (Billy – theatre member) when audiences enjoy the shows. Furthermore, significant others expressed the importance of their loved ones achieving, and seeing them “*blossoming*” (Johnny – significant other) over time.

3.2. Self-relating

The theatre company also helped members to accept themselves. They described their relationship with themselves changing through involvement in the theatre company; “*it’s seeing me in a new light*” (Helena – theatre member), 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*” (Ben – theatre member)

Members also gained a sense of belonging through the theatre company:

“It makes me feel that I’m part of this...even though...I’m an adopted person ... makes you feel at home” (Dave – theatre member)

3.3. Changing perceptions of people with intellectual disabilities

The theatre company also changed significant others’ and community supporters’ perceptions of people with intellectual disabilities. Significant others expressed how their *“perception of the people with disabilities changes, completely”* (Brian – significant other) through the theatre company:

“it does help alter your perception and...it makes you a lot more...understanding”
(Martin – significant other)

“There used to be....an institution in [location name] ...she [wife] was scared of those people...but she’s not scared of anything that goes on here and...or any of the people you know...she’d grown up with this attitude that people with any sort of disability...you wanna shut, should be kept at arm’s length...and now she’s completely the opposite”
(Brian – significant other)

Significant others also described how their perceptions of members’ capabilities was challenged by performances:

“I was actually shamefully expecting a little bit of the awww factor but not at all” (Diane – significant other)

“you just thought my God I wouldn’t of thought you would have done that or you would have done that” (Sarah – significant other)

Community supporters 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” (Jemma – community supporter)

Community supporters 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” (Sam – community supporter)

Members also discussed the impact of performances on the community’s perceptions of people with intellectual disabilities:

“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” (Emily – theatre member)

Significant others also described how the community are *“blown away by what they see and they’re professional as well”* (Julie – significant other). Thus, the performances appear to exceed the community’s expectations relative to what they thought people with intellectual disabilities would be able to achieve.

3.4. Positive effect on wellbeing

Finally, the theatre company was shown to have a positive impact on members and significant others wellbeing. Members described feeling “*more happier*” (Alice – theatre member) since going to the theatre company. Significant others also noticed this in their loved ones:

“he’s [son] just happier in himself” (Sarah – significant other)

Members discussed improved mental health, with one member describing how she was helped with eating difficulties by facilitators encouraging her to “*eat snacks*” (Amy – theatre member), and another member no longer ringing emergency services because the theatre company gives her “*something to focus on*” (Katie – theatre member). Significant others 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” (Sarah – significant other)

Members also described the theatre company increasing their confidence:

“It’s given me ... confidence” (Chris – theatre member)

Significant others noticed how their loved ones are more confident and “*come out their shells*” (Rita – significant other) at the theatre company. Community supporters also saw members’ confidence increase and thought this “*must give more confidence all around*” (Margaret – community supporter).

Significant others identified the positive effect of the theatre company upon their wellbeing, including making their *“life easier”* (Sarah – significant other) 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” (Diane – significant other)

The importance of seeing their children *“learn and progress”* (Tina – significant other) was discussed, and the impact of this on the whole family:

“the person within a family that has got a disability tends to be become the focus rightly or wrongly but it does...it does ease everybody’s feeling of tension and stress as you were saying you know...to have that person happy and settled and enjoying something” (Tina – significant other)

Overall, the theatre company appeared to give significant others *“one less thing to worry about”* (Julie – significant other). Community supporters also discussed the impact of the theatre company upon family’s 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” (Betty – community supporter)

4. A different direction

The final theme encompassed societal difficulties encountered by people with intellectual disabilities and how the theatre company offers something different.

4.1. Societal barriers for people with intellectual disabilities

Members discussed difficult societal experiences relative to having a disability:

“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” (Emily – theatre member)

Members also described limited appropriate services for people with intellectual disabilities as 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” (George – theatre member)

Significant others 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” (Tina – significant other)

Community supporters discussed negative perceptions of people with intellectual disabilities from a historical perspective:

“I mean years ago they never even went to school did they, they never had a chance, they were never given a chance at all” (Lynette – community supporter)

Community supporters were the only participant group expressing hope that perceptions of people with intellectual disabilities were improving, referring to the Paralympics (Robert – community supporter) and children with intellectual disabilities being on television (Margaret – community supporter).

4.2. What makes the theatre company successful

Participants discussed the theatre company's success, comparative to the negative perceptions of people with intellectual disabilities, and inappropriate services elsewhere. Members focused less on what made the organisation successful generally, but stated what made it successful for them personally, including things always being "*done at your own pace*" (Ben – theatre member), and the co-directors being "*a major support*" (George – theatre member).

For significant others, focusing on members' strengths appeared poignant in making the theatre company successful:

"they focus on the ability and forget the dis" (Diane – significant other)

Significant others 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" (Sarah – significant other)

Significant others emphasised the value of the facilitators, through “*putting some vision there*” (Johnny – significant other) 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” (Ann – significant other)

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

4.3. Value of the theatre company

In the context of societal barriers for people with intellectual disabilities 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” (Frank – theatre member)

Members also expressed how going to the theatre company was the “*best thing*” (Dave – theatre member) 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” (Simon – theatre member)

This ‘missing piece’ may relate to the benefits members experience through the theatre company as described in the other themes including making friends, having a purpose and feeling happier. Members also discussed starting similar companies in different places, and a desire to *“have organisations all round the country”* (Billy – theatre member).

Significant others also spoke about the theatre company positively, including it being *“fantastic”* and *“amazing”* (Luke – significant other), and expressed its value in their life:

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

This perceived value meant some significant others 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” (Brian – significant other)

Significant others discussed increasing awareness about the theatre company and improving transport links. They thought it *“would certainly improve other peoples’*

perceptions...if they were out there more” (Brian – significant other). 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” (Julie – significant other)

Community supporters also spoke positively about the theatre company, expressing how *“they are quite special”* (Sam – community supporter). This also led a participant’s son to volunteer:

“he loved volunteering didn’t he and he got a lot out of it” (Claire – community supporter)

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

“it’d help people bond more especially in big towns where people grow up and...don’t know who lives at end of street let alone anything else really” (Lynette – community supporter)

Discussion

Overview of findings

This qualitative study explored the impact of an established theatre company on members with intellectual disabilities, significant people in their lives and the wider community. The specific aims were to understand how people made sense of their involvement in the theatre company, how this impacted upon their understandings and perceptions of

intellectual disabilities, and whether it impacted upon their lives. Two superordinate themes relating to impacts of the theatre company on members were identified, namely members making social and community ‘connections’ through the theatre company, and ‘experiencing parts of life they are often excluded from’. Two further superordinate themes described the impacts of the theatre company on all participant groups, namely participants ‘growing as people’ through their involvement, and seeing the theatre company as offering ‘a different direction’ for people with intellectual disabilities.

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 people with intellectual disabilities (Scior & Werner, 2015) and society’s desire to maintain their distance (Mencap, 2016). The importance of all members having intellectual disabilities 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). The helping aspect of members’ relationships also appeared key, and contrasts with the dependent role in which people with intellectual disabilities 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 people with intellectual disabilities as isolated and invisible (Jahoda et al, 2010). Thus, developing social and community connections through the theatre company appears to promote new understandings of intellectual disabilities for members, significant others and community supporters, in seeing people with intellectual disabilities as integrated, social beings that can take helping roles.

Another understanding that emerged was that people with intellectual disabilities thrive when they are enabled to experience parts of life they are often excluded from. Research suggests people with intellectual disabilities are sheltered from adversity 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 significant others also recognised the importance of this. This suggests the theatre company enabled a new understanding of people with intellectual disabilities for themselves and others that encompassed being able to cope with and thriving off challenges.

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. Donaldson, Dollwet & Rao, 2015; Maslow, 1943; Ryff & Keyes, 1995). Furthermore, the theatre company was also shown to increase members' confidence and helped them to gain more positive self-identities and self-acceptance, benefits also highlighted from other theatre companies for people with intellectual disabilities (Hall, 2010). 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 significant others 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). Thus, the theatre company appeared to enable growth in numerous areas for members', and improved significant others' well-being.

Furthermore, the theatre company changed significant others' and community supporters' perceptions of people with intellectual disabilities. Other theatre studies similarly highlight how actors' capabilities surprise people and change their expectations (Gjærum & Rasmussen, 2010), and how theatre can rewrite identities of people with intellectual disabilities (Calvert, 2009), with this study building upon these findings. This suggests possible ways of changing perceptions of people with intellectual disabilities, which previous reviews have struggled to establish (Seewooruttun & Scior, 2014). Notably, others participant groups did not notice that significant others' perceptions of people with intellectual disabilities change through the theatre company, despite significant others commenting on this themselves. This may indicate that people do not expect families and carers to hold negative perceptions of their loved ones, but this study and previous literature (Heiman, 2002; Lewis & Stenfert-Kroese, 2010) highlights how this can be a challenge for families and carers, with broader implications for supporting these individuals.

The final theme encompassed the 'different direction' the theatre company offers, with participants describing what is different about the theatre company compared to other organisations and services, and what makes it successful. The ethos, location and support offered appeared valued aspects to its success, consistent with literature around other theatre projects (Hall, 2010). These successful components appear to provide people with intellectual disabilities with the opposite of what research suggests are their usual experiences - 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 people with intellectual disabilities from a 'deficit' model (Goodley, 2001; Vorhaus, 2015). This appears to

promote new understandings and perceptions that involve people with intellectual disabilities making decisions, being individuals and possessing strengths.

Although the themes are presented separately, they may be interrelated. For example, members' improved emotional wellbeing as outlined within the 'people growing as people' theme may link to findings from other themes that research suggests contribute to improved emotional wellbeing more generally. This includes: Having social relationships; Helping others; Being connected with wider society (Warin, 2013) ('connections'); Overcoming adversity; Being accepted (Warin, 2013) ('experiencing parts of life they are often excluded from'); Changes in perceptions of significant others and community supporters (Shessel & Reiff, 1999); People with intellectual disabilities internalising these more positive perceptions (Scior, 2003); and improved emotional wellbeing of caregivers (Mencap, 2012) ('people growing as people'). Finally, the positive impacts highlighted in the first three themes may suggest why participants value the theatre company and want others to take 'a different direction', as outlined in the final theme.

Limitations

The majority of participants identified as 'White British'. Given conceptualisations of intellectual disabilities differ across cultures (e.g. Fatimilehin & Nardirshaw, 1994), it is unclear whether the changes in understandings and perceptions of intellectual disabilities outlined would be found cross-culturally. Additionally, participants volunteered to participate, which may open the study to self-selection bias, and a lean towards positive perspectives of the theatre company (Rutherford, 2014). Finally, the community supporters 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 community members without any affiliation to the theatre company.

Using focus groups to collect data has 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. Furthermore, social desirability can affect the validity of focus groups (Stewart & Shamdasani, 2014). In addition, some of the interviews with people with intellectual disabilities were relatively short. Other adaptations could be considered to improve engagement including having a break during the interview, using pictures and/or symbols to support questions, and the option of having a family member or carer present for the interview (Baxter, 2005).

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, significant others or community supporters may have different, but equally valid experiences that the research does not capture.

Implications

The analysis revealed an important process around participants noticing changes in other participant groups. This process between people with intellectual disabilities and significant others is particularly relevant for practice, suggesting significant others 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 significant others was not recognised by other groups, suggesting it may be unexpected that significant others 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. Moreover, a growing acceptance of themselves adds further evidence for people with intellectual disabilities struggling with their identity and self-esteem relative to having an intellectual disability, and implicates a potentially relevant factor to consider when working with people with intellectual disabilities.

This study outlines various benefits theatre can have for people with intellectual disabilities, significant others and community supporters, and supports the development and funding of these services, particularly given government drivers to improve societal attitudes towards people with intellectual disabilities (Parkin, 2016). The findings of this study will be of relevance to, and inform, the development of theatre groups in other geographical areas.

The findings may also have implications that extend beyond people with intellectual disabilities, to other oppressed, excluded and marginalised groups. 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, rather than focusing on individual interventions (Wernick et al, 2014).

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. Furthermore, research considering the impact of the theatre company on local healthcare services would be influential. Thus, it would be interesting to compare rates of referrals in the local area of the theatre company to other areas, to establish whether theatre group attendance acts as an intervention for well-being as the data presented suggests. This may have implications for the funding of such services, as the theatre company presently relies solely on donations to continue running.

Conclusion

This study highlights the changes in understandings and perceptions of intellectual disabilities through involvement in an established theatre company for people with intellectual disabilities themselves, significant people in their lives and supports from the community. These changes include seeing people with intellectual disabilities as sociable, happy individuals who can cope with adversity, 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; the importance of establishing similar organisations elsewhere to enable others to experience this multitude of benefits.

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Table 1. Theatre members' demographics.

Participant pseudonym	Age	Gender	Ethnicity	Living arrangements	Length of time been a member	Number of times attend theatre company per week
Helena	26	F	White British (W/B)	Family home	9 years+	5
Simon	18	F	W/B	Family home	7-9 years	5
Billy	24	M	W/B	Family home	3-4 years	4
Alice	34	M	W/B	Residential home	9 years+	4
Tony	49	M	W/B	Supported housing	9 years+	2
Frank	50	M	W/B	Residential home	4-6 years	5
Ben	22	M	W/B	Family home	6 months-1 year	3
Emily	36	F	W/B	Supported housing	9 years+	5
Chris	25	M	W/B	Supporting housing	6 months-1 year	3
Mary	42	F	W/B	Supported housing	9 years+	4
Katie	30	F	W/B	Supported housing	6 months-1 year	4
George	24	M	W/B	Independent living	4-6 years	4
Dave	53	M	W/B	Residential home	9 years+	3
Amy	28	F	W/B	Supported housing	4-6 years	5

Table 2. Significant others' demographics.

Participant pseudonym	Age	Gender	Ethnicity	Relationship to member	Length of time loved one a member	Ways involved in the theatre company
<i>Focus group 1</i>						
Tina	58	F	W/B	Parent	4-6 years	Mailing list Donate Attend performances
Sarah	54	F	W/B	Parent	1-3 years	Volunteer
Luke	38	M	W/B	Support worker	3-4 years	Ex-volunteer
Ann	54	F	W/B	Support worker	9 years+	Mailing list Donate Attend performances
Cathy	62	F	W/B	Support worker	9 years+	Attend performances
Diane	58	F	W/B	Parent	1-3 years	Mailing list Attend performances
<i>Focus group 2</i>						
Brian	56	M	W/B	Parent	9 years+	Mailing list Donate Attend performances
Martin	61	M	W/B	Parent	4-6 years	Mailing list Volunteer Attend performances
Julie	53	F	W/B	Parent	4-6 years	Mailing list Volunteer Donate Attend performances
Rita	61	F	Not specified	Carer	9 years+	Mailing list Donate Attend performances
Johnny	67	M	W/B	Carer	7-9 years	Attend performances

Table 3. Community supporters' demographics.

Participant pseudonym	Age	Gender	Ethnicity	Ways involved in the theatre company	Length of time been involved	Number of theatre company events attended per year
<i>Focus group 1</i>						
Lynette	63	F	W/B	Attend performances	9 years+	0-2
Victoria	83	F	W/B	Mailing list Donate Attend performances	9 years+	3-4
Jemma	34	F	W/B	Donate Attend performances	4-6 years	0-2
Sam	73	M	W/B	Mailing list Fundraiser Attend performances	4-6 years	3-4
Margaret	73	F	W/B	Mailing list Volunteer Donate Attend performances	4-6 years	3-4
Betty	81	F	W/B	Donate Attend performances	7-9 years	5-6
Robert	63	M	W/B	Mailing list Attend performances	1-3 years	3-4
<i>Focus group 2</i>						
Elizabeth	68	F	Other white background	Volunteer Attend performances	1-3 years	0-2
Sheila	60	F	W/B	Attend performances	7-9 years	0-2
Claire	30	F	W/B	Attend performances	4-6 years	0-2

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

Superordinate themes	Subordinate themes
1. Connections (theatre members)	1.1. Bonds with other members (theatre members) 1.2. Community links (theatre members)
2. Experiencing parts of life they are often excluded from (theatre members)	
3. People growing as people (all)	3.1. Purpose and achievement (theatre members) 3.2. Self-relating (theatre members) 3.3. Challenging perceptions of people with intellectual disabilities (significant others and community supporters) 3.4. Positive effect on wellbeing (theatre members and significant others)
4. A different direction (all)	4.1. Societal barriers for people with intellectual disabilities (all) 4.2. What makes the theatre company successful (all) 4.3. Value of the theatre company (all)