An exploration and proposed taxonomy of leisure-befriending for adults with learning disabilities

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Accessible summary

- Taking part in leisure activities is beneficial, yet many adults with learning disabilities are unable to participate in their preferred activities because of cost, not having anyone to go with, or because they do not feel welcome.
- Befriending is where someone volunteers to act as a friend. Befriending may be a way for adults with learning disabilities to participate in leisure activities with someone who is not a paid carer or family.
- The author spent time with four people with learning disabilities and their befrienders to find out what things they do together and what they both get from it. Friends and family members were also interviewed.
- Participants enjoyed the time they spent together. However, they often did the same activities they would do with paid carers or family and the relationship was sometimes quite professional.
- Befriending could be a way for adults with learning disabilities to have new, beneficial experiences but we need to know more about how relationships work.

Key words
Learning disability; leisure and recreation; natural supports

Abstract

Background

Leisure time for adults with learning disabilities is often diversionary and spent doing passive, solitary, or family-orientated activities. Befriending, as a hybrid 'natural' support, may help adults with learning disabilities overcome the barriers to participation in non-segregated leisure.

Materials and methods

Four case studies of pairs of 'befrienders' and 'befriendees' were recruited purposively. Participant observation was carried out with each case, followed by semi-structured interviews with participants and relevant stakeholders. Data was analysed using thematic analysis.

Results

Befriending activities were mostly limited to enjoyable yet 'casual' leisure activities that adults with learning disabilities might already participate in with family and paid service providers. Negotiating the befriender role between friend and professional was an ongoing challenge.

Conclusions

Outcomes of leisure befriending relationships for adults with learning disabilities are linked to both the nature of relationships and the types of activities undertaken. There are four proposed ideal-types of leisure befriending relationship, yet repeating familiar 'casual' leisure activities means adults with learning disabilities risk missing out on novel leisure and social experiences.

Introduction

People with learning disabilities often require the right kind and amount of support to overcome the barriers faced to full and fair social participation (Duggan & Linehan, 2013; Mayer & Anderson, 2014; Stancliffe, Bigby, Balandin, Wilson, & Craig, 2015). The aim of this paper is to explore befriending as an opportunity for adults with learning disabilities to access leisure in mainstream, as opposed to learning disability specific, settings. 'Befriending' refers to a relationship that is supported by an external organisation or agency in which one person volunteers to act as a friend to another person who has been designated as likely to benefit from the relationship (Dean & Goodlad, 1998). While befriending schemes are popular, there is little theory on which these practices are based or evidence for their effectiveness (Thompson, Valenti, Siette, & Priebe, 2016). Further exploration of active ingredients, appropriate target populations and optimal methods of delivery is required (Mead, Lester, Chew-Graham, Gask, & Bower, 2010; Siette, Cassidy, & Priebe, 2017). Following a qualitative case study design, this paper explores the type of leisure activities engaged in, the roles and decision making of befrienders (volunteers) and befriendees (adults with learning disabilities) within relationships, and the associated outcomes. The paper contributes towards a greater theoretical understanding of befriending as a 'natural' support to facilitate the social inclusion of adults with learning disabilities.

Background

The serious leisure perspective (Stebbins, 2012) proposes three main types of leisure, each of which involves different activities and is associated with different outcomes.   . 'Casual' leisure consists of relatively short-lived, pleasurable activities that require little or no special training, preparation or skill to enjoy. 'Serious' leisure activities are defined as a central life interest in which a person invests physical, intellectual, and emotional energy. 'Project-based' leisure is short-term, moderately complicated activities undertaken once or infrequently.

Leisure for people with learning disabilities has often been viewed as a diversion or time-filler (Patterson, 2001), consisting of passive, solitary or family-orientated activities, often in their own homes (Buttimer & Tierney, 2005; Singleton & Darcy, 2013). More 'serious' leisure pursuits can, however, be particularly valuable for people with a learning disability, akin to work-like activities (Patterson, 2000; Patterson & Pegg, 2009). Many people with learning disabilities value their leisure activities and want to expand their options but lack the knowledge and skills to do so (Bigby, 1992). Support to overcome barriers, seek out information, organise activities, and facilitate inclusion is therefore often necessary (Duggan & Linehan, 2013; Mayer & Anderson, 2014; Stancliffe et al., 2015; Taliaferro & Hammond, 2016; Wilson et al., 2013). Southby (2013), for example, describes the extent to which football fans with a learning disability relied on the support of family, friends, and football coaches to facilitate their serious leisure experiences.

Support can come from paid staff, family members, friends, and co-workers (Buttimer & Tierney, 2005; Stancliffe et al., 2015; Taliaferro & Hammond, 2016). Befriending falls between the 'natural' support provided by friends and family and the professional support provided by care professionals (Duggan & Linehan, 2013). A systematic review of befriending for people experiencing mental health difficulties found there to be a spectrum of befriending-type relationships (Thompson et al., 2016). At one end, relationships are like friendships – open-ended, unstructured, reciprocal, equal, and un-checked – although they are not fully private because of the involvement of third party organisations. In the mid-spectrum, volunteers have a greater role steering conversations/activity and being prescriptive about timing (Thompson et al., 2016). At the far end, the 'professional' befriender is akin to another member of the care team seeking to facilitate the achievement of personal goals through structured support rather than someone who offers something different (Thompson et al., 2016).

For adults with learning disabilities, befriending can be a mechanism to integrate into everyday activities, wider social networks, and function as a route to 'normalisation' in which the community is knowledgeable about disability and values diversity (Amado, DeGrande, Boice, & Hutcheson, 2011; Choma & Ochocka, 2005; Heslop, 2005; Wilson et al., 2013). Relationships are thought to be most beneficial where relationships are built around a shared activity or interest that binds the group (Snow, 2013; Wilson et al., 2013). However, Hughes and Waldenm (1999) found no evidence for increases in social network size following a befriender programme for people with learning disabilities. Few befriending activities specifically aim to increase the social inclusion of people with learning disabilities, preferring activities at home or in segregated groups in the community were interaction with others is unlikely (Heslop, 2005). Moreover, few befriending schemes for people with learning disabilities collect evidence of the effectiveness of their service (Howarth, Morris, Newlin, & Webber, 2016).

Methodology

To explore the complexity of befriending as an opportunity for adults with learning disabilities to access mainstream leisure a case study design was adopted. Case study research leads to greater understanding through in-depth examination of a particular subject(s) (the case(s)) and the related contextual conditions (Bryman, 2016).

Sampling and recruitment

Four cases, each comprising a befriender-befriendee pair and people close to them able to offer insight on the befriending relationship, were recruited (see Table 1).

*****INSERT TABLE 1*****

Sampling followed a purposive, opportunistic strategy (Bryman, 2016). One national and one local charitable organisation administering a befriending scheme for adults with learning disabilities agreed to share information about the research with befriender-befriendee pairs who they felt may be interested in taking part. Inclusion criteria were that pairs were taking part in activities together in a mainstream rather than segregated or private setting and that adults with learning disabilities enjoyed talking about their befriending activities and experiences.

Following an introduction from the befriending organisations, the researcher made contact with participants to explain the project and to plan data collection. Contact with befriendees initially went through a care provider (i.e. supported housing manager, parent) to ensure the support of gatekeepers (Crook, Tomlins, Bancroft, & Ogi, 2016). Befrienders and befriendees were asked to nominate interviewees who could offer an informed perspective about their befriending relationship (i.e. parent, carer, friends, employers). These people where contacted by telephone to discuss participation and arrange data collection.

Consent and ethics

The research received ethical approval via the XXXXX University ethics procedure. Ensuring befriendees knew what they were signing up for was a challenge; more than just participating in a series of data collection activities, they were being invited to open-up their lives to outside scrutiny (Booth & Booth, 1994). The notion of 'ethical research' was therefore not seen as a single issue but constructed during the research process (Swain, Heyman, & Gillman, 1998). Two written information sheets explaining participants' rights and responsibilities in the research process were given to participants prior to data collection. One used simplified language and pictures to explain the research process (Rubin et al., 2001). Participants indicated their consent to take part by signing a written consent form. Parents or carers did not give proxy consent on behalf of adults with learning disabilities as this would have undermined inclusivity and disempowered participants. (In practice, parents or guardians were required to give consent in their roles as gatekeepers). Gaining consent was also a continuous process achieved through interaction between the researcher, participant, and trusted individuals close to the participants (i.e. parent, paid carers).

Data collection

As the research was exploratory in nature, qualitative methods were employed. For each case, participant observations of befriending activities were conducted. Participant observations served multiple purposes: (1) to observe and gain a greater understanding of the befriending relationship, (2) to help build a rapport between researcher and participants, and (3) to provide a stimulus for conversation in follow-up interviews. Written field notes were shared with respective befrienders but not with befriendees to verify the accuracy of contextual information (i.e. when relationships started, time spent together, frequency of visits, etc.), which did not need to be double-checked. Not corroborating field notes with befriendees was a necessary pragmatic step given limited time and resources to develop a more inclusive approach, although it could be interpreted as exclusionary.

Observations were followed up with fourteen semi-structured interviews, covering how and why the relationship started, activities undertaken during befriending, the relationship between befrienders and befriendees, outcomes/impact, and process issues (i.e. recruitment processes, training). Where possible, interviews were conducted face-to-face in a place convenient for participants. Two interviews (Case 3 Parent and Case 3 Employer) were conducted over the telephone. With participants' consent, interviews were audio recorded. Befriendees appeared to understand the questions, although they commonly gave short or single word answers to questions. To aid communication, interview questions were slowed down and/or rephrased in order to illicit more

detail (Patterson & Pegg, 2009). Having built rapport with participants (via participant observation) helped facilitate discussion beyond the 'official story' participants might tell more casual inquirers (Lesseliers, Van Hove, & Vandevelde, 2009).

Data analysis

Data was analysed using thematic analysis (Braun & Clarke, 2006). Audio recordings were transcribed verbatim. Transcripts and case reports were then coded for each case. Themes and sub-subthemes were identified for each case before commonalities and differences across the cases were identified using a cross-case matrix (see Table 2).

*****INSERT TABLE 2*****

Results

The cases examined in this paper are Ian & Laura, Lesley & Trisha, Dave & Eleanor, and Dom & Kelly (all pseudonyms). Descriptive information about the cases is presented in Table 3.

*****INSERT TABLE 3*****

Activities

The befrienders and befriendees in this research undertook a range of leisure activities in mainstream public settings as opposed to home or segregated, disability-specific settings, including eating and drinking out, shopping, theatre and music performances, bowling, walking, and visits to tourist attractions/places of interest. However, whilst being present in the community, all the activities undertaken were carried out individually by befrienders and befriendees rather than collectively as part of, for example, a team, group, or club with other people.

Deciding what activities to do was a collaborative process between befrienders and befriendees. Befrienders typically proposed ideas for activities that they thought would be of interest and befriendees made the final decisions. Befriendees were often reluctant to suggest activities themselves or struggled to articulate their own ideas. One befriendee said:

> *"It's always hard to know what – what to see or do together when you're available, you know" (Case 3, befriendee)*

Across the cases, there was little external input in discussion about activities. Dom's mother and support staff had suggested some activities that they felt would benefit him (i.e. cooking, reading). Kelly described being uncomfortable encouraging Dom to do activities he had shown no interest in doing with her and felt it reflected a more professionalised relationship.

Ian & Laura and Kelly & Dom decided what activities to do together on the day they met. While deciding in the moment potentially allowed for more spontaneity, this approach generally resulted in repeating activities. Kelly explained that when she is tired from work, it is easier to propose activities that she knows Dom will like rather than experimenting. Whilst repeating activities that befriendees enjoyed allowed participants to develop relationships and social connections with other people in the setting, such as café or restaurant staff, Ian & Laura and Dom & Kelly each appeared to be developing routines very similar to those that Ian and Dom, as service users, do with their paid support workers. This risked befriending relationships stagnating or becoming too like a service relationship. A member of supported housing staff reflected on Dom's relationship with Kelly:

> *"I think he's losing the concept of a friendship…When he's out with staff he knows on a Monday with staff he does that; on a Tuesday with staff he does that…with a friend you'd*

mix it up a little bit, and I don't want [the befriender or befriendee] to think it's just another staff member task that they're doing" (Case 4, Service staff)

For Lesley & Trish and Dave & Eleanor, their activities had evolved from meeting every week or two weeks for a relatively short time to meeting once a month and spending longer together doing a 'bigger', pre-planned activity, such as trips to local tourist sites, theatre shows, or music gigs. For both pairs, it appeared their time spent together was more varied, and potentially more enjoyable and meaningful for both befrienders *and* befriendees. Identifying and organising such activities required a greater investment of time and effort. Lesley described planning activities based on what she knew about Trisha's life history, interests, and capabilities:

"I'm trying to kind of work out what is the kind of things that she would like to do…to kind of create some of those opportunities for her, to give her a little bit more variety in her life…bearing in mind, you know, what it is that she likes to do" (Case 2, Befriender)

A beneficial relationships?

The befriending relationship was thought to be unique, with different 'rules' than relationships that either party had with other people. Befriending appeared to be mutually beneficial for befrienders and befriendees across all cases. The activities were largely enjoyable and something to look forward to; an opportunity to do new things, meet new people, and get out of the house and be in the community; and supported individual wellbeing. A supported housing staff member spoke about the impact on Ian:

"It's definitely had a positive impact on him…I think he can get quite lonely at times with not having many friends and people round him. So, it's definitely made him a happier person… they're his favourite day" (Case 1, Service staff)

For befriendees, befriending promoted independence away from services and/or family and improved their confidence and skills around communication. Befriendees seemed to value that the relationship was one-to-one and just for them, rather than having to be shared with other service users or siblings. All befriendees described their befriender as a friend. The relationships appeared to be less hierarchical and more flexible than their relationships with family or paid support staff. Befriendees recognised and appreciated that the relationship was voluntary and that befrienders wanted to spend time with them. A number of interviewees spoke about this dynamic:

"He sees it as special…He understands that, you know, she's doing it voluntarily" (Case 1, Service staff)

"I mean, I think it's just nice to go with somebody – to go and do more stuff with somebody you get on with, rather than your family, say" (Case3, Befriendee)

Significantly, befrienders became a confidant – separate from services and family – with whom befriendees could share their thoughts and feelings. Both Laura and Trisha similarly described their befriender role in terms of being a trusted ally:

"[I let Ian] have a good old moan about the people in his life…I don't think he'd feel comfortable saying those sort of things to another member of staff" (Case 1, Befriender)

"When she's got something she needs to get off her chest, or when something's troubling her…she will say…and 'can you help me sort it out?'" (Case 2, Befriender)

Befrienders also valued the uniqueness of the relationship; befriending was a break from the norm and an opportunity to do things with someone with whom they would not normally. The relationships specifically supported befrienders' employability (though skill acquisition and experience) and was an opportunity to 'give back'. Laura described the benefits to her:

> "It's a connection for me also because I can become quite isolated…I struggle with bouts of depression and if I am feeling quite low myself it's quite beneficial for me…lifting my spirits…I'm hoping that in the future it will be beneficial for me finding employment" (Case 2, Befriender).

However, befrienders were more aware of an ongoing challenge negotiating between a friend and professional/service relationship. They had a greater caring responsibility towards befriendees than towards other friends, such as helping befriendees to travel or handle money. Laura described her relationship with Ian in terms of an extended family member:

> "I think it feels like a cousin, or maybe I'm his niece. Like a sort of loose family relationship…there is an element of looking after that person, more so than you would with a friend" (Case 1, Befriender).

Kelly felt that her relationship with Dom could feel like delivering a service rather than a relationship between peers – *"probably more supportive than friendship"* (Case 4, Befriender) – because they largely do the same activities each week. Eleanor appeared concerned about her relationship with Dave becoming too familiar, saying that she had to ask him not to call or text her too much. Conversely, Lesley felt her friendship with Trisha was prevented from becoming more 'natural' by the organisation administering the befriending scheme; she had wanted Trisha to attend an outdoor show with her and her family but was told this was not allowed.

Outside of befrienders and befriendees, befriending helped relieve pressure on (residential) services to find stimulating activities for residents. Whilst we cannot say whether public perceptions of learning disability changed because of the befriending activities, it would appear that befriending provided opportunities for interaction between adults with learning disabilities and other people in the community.

A proposed taxonomy of leisure befriending

The types of activities undertaken, decision-making processes, roles of actors, and outcomes of befriending relationships appear to be interconnected. A taxonomy of leisure-befriending for adults with learning disabilities is therefore proposed, drawing on the serious leisure perspective (Stebbins, 2012) and Thompson et al's (2016) spectrum of befriending-type relationships. Seen as overlapping continuums – casual-serious and friendship-professional – these aspects produce four quadrants into which befriending relationships for adults with learning disabilities can be classified; casual/friend, serious/friend, serious/professional, and casual/professional (see figure 1). Each quadrant represents an ideal type of leisure-befriending relationship, with associated behaviours and outcomes.

*****INSERT FIGURE 1*****

Casual/friend befriending can be thought of as relationships that are open-ended, reciprocal and equal, and not continuously monitored. Activities are undertaken purely for pleasure and are relatively short-lived, requiring little or no special training, preparation or skill to enjoy. The cases examined here, to varying degrees, fit into this quadrant most comfortably. Serious/friend befriending relationships are equally open ended and reciprocal but are based around an activity

that requires specialised skill/knowledge in which both parties have an explicit interest. If Dave and Eleanor, for example, were to undertake more activities themed around their shared interest in theatre and the arts their relationship could be seen as a more 'serious/friend' rather than 'casual friend'. Within both casual/friend and serious/friend befriending, activities are likely to be negotiated between befrienders and befriendees and equally of interest for both parties.

Serious/professional befriending relationships also take part in 'serious' leisure activities but the relationship is formalised and actively managed by an external organisation. The relationship is akin to mentoring and the intention is to facilitate the achievement of personal goals through structured one-to-one support. The befriender is another member of the care team rather than someone who offers something different. Finally, casual/professional befriending involves a similarly formal relationship to serious/professional befriending but the pair take part in casual leisure activities together. Dom and Kelly's repetition of the same casual activities that principally Dom enjoy means that they may be within the casual/professional quandrant; Kelly herself recognised this in describing her role as akin to a service provider. Within both serious/professional and serious/casual befriending, decisions concerning activities undertaken are unequal. Power is either deliberately given exclusively to befriendees to promote empowerment, or third parties (i.e. care providers) are involved to organise activities towards pre-set goals or targets.

Discussion

Occupying a space between the 'natural' support of friends and family and the professional support of paid care workers, befriending is commonly seen to provide people with learning disabilities access to social and leisure opportunities that otherwise might not be available to them (Bigby & Wiesel, 2011; Buttimer & Tierney, 2005; McConkey & Collins, 2010). The data collected here supports befriending as an opportunity for adults with learning disabilities – and volunteers – to take part in pleasurable leisure activities and achieve individual, social, and inclusion benefits (Choma & Ochocka, 2005; Clement & Bigby, 2009; Heslop, 2005; Wilson et al., 2013). It is apparent that befriending relationships can be extremely valuable (Duggan & Linehan, 2013; Zakrajsek, Hammel, & Scazzero, 2014), especially for those most isolated. However, questions remain about the novelty of some of the leisure activities and relationships observed here. The activities undertaken were more-or-less casual leisure activities and often not different to the activities that people with a learning disability typically engaged in with paid support workers and/or family members. Similarly, whilst a spectrum of befriending-type relationships is possible (Thompson et al., 2016), the relationships here very often reflected the professional relationships adults with learning disabilities experienced in other areas of their lives rather than being 'friends'.

To be most beneficial, leisure-befriending relationships involving adults with learning disabilities need to develop from casual to more serious leisure activities (i.e. Patterson & Pegg, 2009; Southby 2013) and from 'professional' to 'friendship' orientated relationships (i.e. (Fillary & Pernice, 2005). This could help achieve a better balance between access to both serious and casual leisure that, according to the 'serious leisure perspective' (Stebbins, 2001), is needed for a good personal and social life. Whilst some leisure-befriending relationships might do this over time themselves, others may need additional support. The proposed taxonomy provides a map of types of leisure-befriending relationships for adults with learning disabilities and could be a used to identify areas of development.

Practically, building befriending relationships around shared activities and interests is one potential method for developing leisure-befriending relationships to provide a more novel experience (Anderson & Kress, 2003; Brooker et al., 2015; Snow, 2013; Wilson et al., 2013); specific roles are

more clearly defined and adults with learning disabilities would be actively engaged in generating a social identity as part of a particular group or social activity alongside volunteers and fellow participants (Heslop, 2005). How 'friendly' befriending relationships are is largely a matter of how equitably power is shared between participants. The onus appears to be on befrienders to strike the correct balance between facilitating and challenging befriendees as part of their remit to provide the appropriate support to overcome barriers to inclusion (Duggan & Linehan, 2013; Mayer & Anderson, 2014; Stancliffe et al., 2015; Taliaferro & Hammond, 2016; Wilson et al., 2013). Both these actions rely on the availability of appropriate volunteers and volunteer supporting organisations.

Supporting or managing befriending relationships to be a certain way, in order to exploit areas of deficit in adult with learning disabilities' social or leisure activities, may itself undermine the appeal of the 'naturalness' of befriending relationships. We must also consider whether this is what participants want from relationships. Whilst volunteers are typically already aware of the constraints on their befriending relationships, adults with learning disabilities might not appreciate the intrusion into a relationship they enjoy. The most successful relationships were those where befrienders were sufficiently knowledgeable (i.e. of learning disability, awareness of their role) and skilled (i.e. interpersonal, communication) (Wistow, Perkins, Knapp, Bauer, & Bonin, 2016), and where befriendees were willing and able to embrace new challenges, for relationships to progress on their own terms. There appears to be a role for befriending-organisations here in understanding the purpose of relationships, managing expectations, and providing appropriate support to both parties (Bigby et al., 2014).

This paper presents an insight into the experience of leisure participation through befriending for adults with learning disabilities, responding to calls for such mechanism to be better understood (Siette et al., 2017). However, the findings should not be treated as entirely generalizable because of the small sample size. It was beyond the remit of this work to assess the extent to which leisure-befriending served to 'normalise' learning disability. Undertaking further work in this area, specifically capturing the views of community members, is key in this regard. Further exploration of active ingredients, populations, and methods of delivery concerning befriending for adults with learning disabilities is required. Further consideration and testing of the proposed taxonomy is also required.

Conclusion

The outcomes of leisure befriending relationships for adults with learning disabilities are linked to both the nature of the relationship and the types of activities undertaken. Whilst there are four ideal types of leisure befriending relationship, repeating familiar 'casual' leisure activities means adults with learning disabilities risk missing out on novel leisure and social experiences. The proposed taxonomy advances understanding of leisure-befriending relationships and could be used to guide relationships towards leisure and social opportunities that might not otherwise be available to adults with learning disabilities.

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