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Article

The Challenges of Safety and Community Integration for Vulnerable Individuals

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Abstract: Although community inclusion brings a number of advantages for vulnerable individuals, it can also entail a range of challenges, and draws in issues of safety and security. This qualitative psychological study, therefore, aimed to explore the challenges being faced by two groups of vulnerable individuals: those with intellectual disabilities and dementia, and how these could be addressed in order to establish a community that is safe and welcoming for all. Interviews and focus groups were conducted with a range of community stakeholders—for instance, local businesses, residents, and individuals with intellectual disabilities, dementia and their carers—and data was thematically analysed to explore the issue of inclusion and participation particularly in relation to stigma and prejudice, self-worth, social isolation and feeling safe. As well as highlighting practical issues regarding inclusion and support, the work emphasised the psychological dimension, linking to a multi-faceted conception of community participation. While significant work is already addressing issues of risk and safety for vulnerable populations (such as “Keep Safe” schemes), the work described here leads to an alternative conceptualization, tied to notions of kindness in communities with a view to crafting communities capable of safely welcoming a wider variety of marginalized groups.

Keywords: community safety; intellectual disability; dementia; vulnerable adults; discrimination; inclusion; barriers to participation; psychological perceptions of safety; kindness; inclusive design

1. Introduction

Human beings have a basic need to belong, which causes them to affiliate, to join and be members of groups. Such affiliation results in successful connections to others, producing heightened self-esteem and self-worth [1]. Group affiliation not only brings benefits for individuals themselves, but can also afford opportunities to further shape the group and its surrounding community context. Almost 100 years ago, Dewey recognized that engaging citizens in meaningful participation in local practices and decisions that shaped their lives led to increased participation at a community level which protected and advanced citizens’ interests within broader society [2]. Existing research also identifies a number of other advantages of community participation, such as health and social benefits [3], strengthening relationships between members [4], enhancing services and preventing crime [5].

Community participation has both a physical dimension, in terms of the engagement behaviour itself, and a psychological dimension which reflects motivational, emotional and attitudinal aspects. Sense of community i.e., feelings of membership or belongingness to a community group [4] is a fundamental psychological aspect of participation, and it is essential to the development and empowerment of local communities; especially those that are marginalized and disadvantaged [6]. Its absence presents a significant barrier to community participation, and brings to the fore concerns

about safety and security, in both practical and socio-emotional terms, particularly in relation to marginalized groups; a significant issue which has been highlighted previously within the literature, e.g., [7–11]. The multi-faceted perspective on community participation, outlined above, provides a valuable lens through which to view the issues of safety and security for more vulnerable members of society. Previous research has focused on teaching road safety [12], first aid skills [13], and use of public transport [14,15]. However, such a multifarious perspective on community participation highlights the need to not only address these very real and practical issues, but also psychological ones, such as belongingness and sense of community. Existing research indicates that community perceptions of vulnerable populations can play a role in marginalization [16], and vulnerable groups can be more susceptible to harm due to their minority status [17] and becoming “lost” in the community [8]. Encouragingly, the importance of social connectedness is reflected in a variety of government policies within the UK. For example, the Scottish Government’s first strategy in 2018 aimed at tackling social isolation and building stronger communities makes specific recommendations to address stigma and discrimination, improve opportunities for people to connect and further empower communities themselves [18].

Everyone has the right to access their local community, though for some people this can be more challenging than others: individuals with an intellectual disability are at greater risk of isolation within their communities [19]. Individuals with an intellectual disability are “one of the most marginalized groups in Western society, experiencing severe personal, social and institutional abjection and discrimination” [20] (pp. 107). Heiman and Shemesh [11] report that, compared to students without intellectual disabilities, students with intellectual disabilities report more cyber victimization, and a plethora of research has identified that people with intellectual disabilities are at an increased risk of abuse in differing forms [10,21,22]. Available evidence indicates that rates of social and community inclusion for people with an intellectual disability generally are low [23]. Individuals, especially those with mild disabilities, have more negative perceptions of key aspects of the environment such as whether they like the neighbourhood and perceived community spirit; access to shops, education and health care, and feelings of safety and fear of crime [9].

Insight into how inclusion may be promoted comes from the observational work of Craig and Bigby (2015) who examined how community groups respond to and support the participation of people with a moderate level of intellectual impairment. Findings indicate that successful community participation is characterised by equality i.e., the individual with a learning disability feels and is perceived as an equal and full member of the group, is engaged in a high degree of co-operative working within the group and that membership is rewarding for all members [24].

Inclusion brings challenges for all concerned: the person with an intellectual disability may be concerned about participating; support staff and family carers may want to protect them from discrimination and therefore restrict opportunities; and there may be practical challenges in terms of time and resources to support the activity. Community groups too face challenges both practically in terms of risk management and socially in terms of attitudes and beliefs as the inclusion of an individual with an intellectual disability may change the dynamic and initial shared vision of the group [23]. Therefore, further research is required to examine community views and community responses to the inclusion of people with an intellectual disability generally, and to explore the views, experiences and challenges that community participation brings for people with an intellectual disability and their carers.

People with dementia represent another vulnerable population for whom the advantages of community participation are increasingly being recognised. Loneliness is a significant issue for people with dementia, as noted by Moyle and colleagues [25]. In their exploration of the experiences of people with dementia and those caring for them, they found that carers attributed the socially isolating behaviour of peers to a lack of understanding of dementia, and a fear regarding how to communicate or interact. Bowes et al. [26] identify that participating in community leisure activities has benefits beyond those associated with remaining physically active when an individual develops dementia, as they can promote both social and mental well-being. International work has further underlined the impact of stigma and lack of understanding [27]. These issues are also familiar to

people with intellectual disabilities, and the ways in which society can at times fail to recognise their rights is mirrored in the experiences of people with dementia. The Dementia Engagement and Empowerment Project, for example, highlights the rights of people with dementia to have access to information they can understand, and makes recommendations in this regard [28] which share much with guidance around accessible materials for people with intellectual disabilities. Data also indicates the relatively low rates of inclusion for people with dementia. For instance, Morgan et al. [29] identified eight barriers that individuals with dementia face when accessing community-based services, such as lack of awareness, challenges in service delivery, and beliefs and attitudes: the same factors have been identified in relation to people with intellectual disabilities [7]. Snyder and colleagues [30] termed people's feelings of decreased self-worth in being part of the community as "devaluation", and in their review of literature on the needs of people with dementia, van der Roest et al. [31] identified that the most frequently reported needs of people with dementia are to be accepted and respected as they are, which is not necessarily realistic in terms of being safe and secure in the community. Indeed, there is a plethora of literature focusing on the stigmatic and prejudiced attitudes towards people with an intellectual disability or dementia (e.g., [32–35]) which undoubtedly contributes to diminished feelings of safety and inclusion in the community.

Existing research illustrates the extent to which both dementia and intellectual disability populations experience similar physical and psychological barriers in terms of safe community participation. Although the available literature indicates that increased community participation raises a number of challenges for adults with an intellectual disability or dementia as distinct populations, a detailed understanding of community participation and safety issues and how they overlap for these populations remains underexplored and unspecified. The project reported below aims to address this issue by considering the rich contextualized insights from a community-based qualitative study. The opportunity arose to work with a community who were motivated to make their community more inclusive for all and who were keen to understand the barriers to participation and the challenges to safety and security it entails. Similar to work in Ireland which sought to use a Universal Design Approach to produce guidance around dementia friendly hospitals [36], the work described here sought to use the experiences of people with intellectual disabilities and/or dementia and those who care for them to generate insights that would help craft a community that was safer and more welcoming for all. The specific aims for the study were to identify the following:

- What are the key issues that people with an intellectual disability and/or dementia, and their carers, face in community settings?
- How do community members perceive the needs of people with an intellectual disability and/or dementia?
- What support is required to accommodate the needs of individuals with an intellectual disability and dementia within the safer and friendlier community initiative?

2. Materials and Methods

In this section we report the finding of a community-based qualitative study, based in a small town in the West of Scotland that was interested in making their community more inclusive and safe for all community members, especially vulnerable individuals such as those with dementia and/or an intellectual disability.

2.1. Participants and Recruitment

Before recruitment commenced university ethical approval was sought and received. Participants were self-identifying and recruited via convenience and snowball sampling: existing community groups (e.g., carers/support groups), and individual carers of vulnerable individuals known to the members of the community group leading the initiative were contacted and asked if they had members or friends who might also be interested in participating. Participants were also recruited more generally within the community in response to the opportunity to participate in a

community engagement exercise advertised via local community links. Recruitment snowballed as other community stakeholders heard about the project and were keen to be included, resulting in interviews and focus groups being conducted with community members with and without any form of disability, local businesses, carers, volunteers, local councillors, church groups, community group leaders and charitable organisations. Definitions of intellectual disability have habitually made reference to IQ criteria along with other defining features. However, a more pragmatic concept of learning disability, less bound by IQ criteria, is beginning to emerge. Within the recent Learning Disability (the preferred term for intellectual disability in Scotland) Strategy published by the Scottish Government, the definition used (and one developed with the involvement of people with intellectual disability themselves) was: “A learning disability is significant and lifelong. It starts before adulthood and affects the person’s development. This means that a person with a learning disability will be likely to need help to understand information, learn skills and live a fulfilling life. Some people with learning disabilities will also have healthcare needs and require support to communicate.” ([37], pp. 9).

With regard to dementia, within the World Health Organisation global action plan on dementia, it is described as: “an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person’s ability to maintain the activities of daily living”. ([38], pp. 2).

For the purposes of this work, participants were recruited as outlined above from a range of community services or local support groups for people with intellectual disability, or people with dementia. No formal assessment of intellectual disability or dementia was undertaken by the project team, or required to be evidenced and so, in effect, we accepted people as self-identifying as having an intellectual disability and/or dementia.

Thirty-five participants were recruited including older adults with dementia and/or an intellectual disability (N = 5), carers/support workers for people with dementia and/or an intellectual disability (N = 9), community and charity group leaders and volunteers, representatives from local businesses and church groups, and other interested community members (N = 21). Thirteen one to one interviews (with eight carers/support workers for adults with an intellectual disability and three individuals with dementia) and two focus groups (one focus group with 21 community stakeholders, and one focus group with one support worker from a local charity and two individuals with an intellectual disability who attended that group on a regular basis) were conducted.

2.2. Data Collection and Analysis

Discussions with vulnerable adults and carers/support workers were focused by using a semi-structured interview schedule that probed issues such as the extent and experience of community participation, preferences for community participation, barriers to community participation, and the support required to enable increased participation in community events. Discussions with community stakeholders were also focused using a semi-structured interview schedule that contained trigger questions to probe issues such as their perceptions of the needs and abilities of vulnerable individuals, barriers to community participation and what support (in terms of education, training and adaptation) is required to increase the safe participation of vulnerable individuals within the community.

All discussions were audio-recorded, transcribed verbatim and thematically analysed [39]; a method which is in keeping with existing research with similar populations [40,41].

Data collection totalled 472 min. Individual interviews ranged from 10–53 (average: 29) minutes and focus groups ranged from 46–53 (average: 49) minutes in length. In accordance with ethical clearance all participants were fully informed of the aims of the study and their right to withdraw (both verbally and via an information sheet) and gave signed consent to participate and were debriefed after the study (both verbally and via a debrief sheet). Participants’ identities were protected by using pseudonyms, and only the named authors had access to the recordings and transcripts, which were stored securely.

3. Results

The following section outlines the key themes concerning the integration of vulnerable individuals in the community illustrated with quotes from various community members. These themes focus on (1) stigma and prejudice, (2) self-worth, (3) social isolation, and (4) feeling safe. In general, these themes illustrate barriers to community inclusion. However, participants also reflected on how some of these difficulties may be overcome and identified a range of potential enablers consisting of the provision of practical and emotional support captured by the theme of (5) supporting community participation.

3.1. Stigma and Prejudice

Erving Goffman [42] (pp. 3) is credited for his seminal work regarding stigma, defining it as, “[an] attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted and discounted one”. The term was used frequently by participants as a barrier to the development of an inclusive community, and there was reference to the fact that other people’s attitudes have an impact on the lives of people with an intellectual disability and dementia, highlighting the need for understanding and learning on the part of the community:

“I don’t know if there’s just not the understanding there, the stigma, I don’t know, but I’ve had a few people say certain places they go they feel a bit even more isolated because they’ve made an effort to go along to an activity and then they’re not really included in it” (Support worker for an individual with an intellectual disability).

It is clear from the above quote that there is a direct link between stigma and inclusion, or lack thereof. The participant identifies that although there are community opportunities for the more vulnerable members of the community, they still may not be included: that in theory there are opportunities, but in practice there is still exclusion. However, participants, too, realised that this may not be a barrier that is specific to the current community, but representative of a wider problem: a finding consistent with existing research [43]. For example,

“You’re always going to get people in communities that are out unfortunately to target vulnerable people but that’s everywhere” (Support worker for an individual with an intellectual disability).

“I think you never get away from the fact that some people are biased... there’s always people who are gonna treat them differently, but as long as they’re being treated well by the most people, I think that’s the important part” (Community Group Leader).

The above quotes demonstrate that the targeting of vulnerable individuals appears to be universally accepted: it is found “everywhere”. This normalisation is concerning as it suggests a pervasive problem in society, and even though it is mentioned that “most people” treat such groups well, it suggests that more community education is required to ensure that people with intellectual disabilities and dementia are not denied opportunities to engage in the community, and are supported to do so. One study, for instance, demonstrated that disabled youths described feeling safe in their community only half as often as nondisabled peers [44]. This highlights the importance of making spaces safe for individuals with vulnerabilities, which is the whole premise of dementia friendly communities: a place or culture in which people with dementia can be empowered, supported and included in society [45–48]. Alzheimer Scotland determines that a dementia friendly community is made up of the whole community; people who are committed to working together and helping people with dementia to remain a part of their community and not become apart from it [49]. This is particularly important in the current study, as exclusion was identified as an issue for the more vulnerable members of the community. However, that is not to say that only individuals with dementia benefit from such cultures: they can be beneficial for all [50].

3.2. Self-Worth

Issues of prejudice and stigma can be an even greater barrier to safety and community participation if they are manifested as hate crime. Traditionally focused on religion, race and sexuality, disability hate crime is a relatively more recent topic [51]. Participants identified that for the more vulnerable members of the community, there was evidence of “mate crime”; a play on the term “hate crime”, it refers to a specific form of hate crime against disabled people, predominantly those with intellectual disabilities [52].

“It’s not just disability hate crime, there’s mate crime as well and it’s where friendships are struck up because there are a lot of people with an intellectual disability in the area that are vulnerable that don’t have support” (Support worker for an individual with an intellectual disability).

“There’s people that can take advantage of people with an intellectual disability as in, ‘oh they don’t get support in their support hours’ and maybe target them for like mate crime, you know, ‘oh, I’ve not got any money today’ ” (Support worker for an individual with an intellectual disability).

In the above quotes, there is acknowledgement of mate crime happening to some of the individuals in the community under consideration. It is identified that friendships are established with vulnerable people who do not have support, on the proviso that they give them money, with such exploitation being identified as a common feature of the “crime” [53]. Individuals with intellectual disabilities may not realise that they may be taken advantage of in such a way, and even if they do, research has shown that disabled people generally face barriers to reporting abuse (e.g., [10,54–56]). Grundy [57] details an initiative focused on mate crime: “Safety Net” was established in 2009, aiming to prevent the exploitation of people with intellectual disabilities by those claiming to be their friends. The project reported the main finding to be that people with an intellectual disability can struggle to recognize when they are being exploited [58]; a finding replicated in further research [52].

This has clear links to the safety of the more vulnerable community members, however, feeling unsafe in the community is not only linked to social factors within the community and the incidence of crime, it can also be attributed to psychological resources such as fear of crime, motivation and low self-worth, which may also function as barriers to community participation. O’Rourke and colleagues [59] discussed how people with an intellectual disability have a desire to engage more in community activities, and indeed, respondents in this study spoke about the benefits that are obtained for individuals by being included in the community, as detailed below:

“Feeling wanted and needed and for themselves, just to get out” (Carer of someone with Dementia).

Participants regarded inclusion as important as it was related to self-worth, which was also identified as a barrier to inclusion, in that if individuals had feelings of low self-worth, they are less likely to want to be actively part of the community. This presents somewhat of a dilemma: individuals do not have the self-worth to feel a valued part of the community, but not being part of the community may enhance the feelings of low self-worth. Furthermore, lack of participation reduces the opportunity to become aware of the actual nature of the community and this lack of understanding and experience may help reinforce negative perceptions of the risks and increase concerns over safety that further restrict motivation to engage with the community. This then puts vulnerable community members at risk of social isolation, as detailed in the next section.

3.3. Social Isolation

Although increased community involvement is assumed to entail a degree of risk as detailed by aforementioned research (e.g., [31–34]), a number of community stakeholders identified social

isolation as a major risk due to a lack of community participation. Although some of this risk may be attributed to geographical location, much is due to social factors. Research suggests that rates of social and community inclusion for people with an intellectual disability generally are low [23,60] and that the barriers faced by people with intellectual disabilities in their everyday lives indicate the importance of social knowledge and skills to help facilitate social integration, the role of support, and the impact of community factors such as lack of amenities and attitudes [7]. Consider the following:

“Isolation must be hell, and to feel needed and, you know, it must be awful being lonely and seeing nobody from day to a day, and there must be quite a few like that” (Carer of an individual with Dementia).

It was worrisome that isolation was being identified in the current project as a major risk factor: there are people within the community that do not see other people on a day to day basis or are not able to pursue friendships. Despite isolation being a huge concern amongst all participants—and being identified as a problem for the community—participants identified that support is needed to tackle the issue:

“You see so many of these people that are in isolation and you think, ‘I wish there was a way just to get them altogether’, but again it would be about they’d need lots of support” (Support worker for an individual with an intellectual disability).

Often, community participation is linked to leisure, and a number of barriers to participation in leisure activities for such vulnerable groups were identified. Such barriers may be intrinsic in nature; attributable to characteristics of the individual such as communication and social skills and degree of dependency on caregivers, or more environmental factors such as perceived attitudes of others and more practical issues such as access [61]. Here, too, constraints often interact and even when practical issues are addressed such as the availability of transport, social barriers such as the attitudes of carers remain [62]. Research has also examined how dementia can restrict participation in leisure activities which also highlights the importance of environmental factors concerning accessibility in relation to transport, toilets, venues and carer influences concerning fear of the person with dementia getting lost and the restriction choice of activities [43], as detailed by the following:

“If they didn’t have the support to go to them, you know, they probably wouldn’t be able to access them. Sometimes as well if there’s things on they might want to go to, but if it’s out-with their support hours, that might be a barrier” (Support worker for an individual with an intellectual disability).

Despite such barriers, community members do recognise opportunities to take part in community initiatives:

(MyBus: door to door transport) “so you could be picked up from your house, taken to the shop and then picked up again as a group which I think it sometimes—people feel safer that way” (Support worker for an individual with an intellectual disability).

(The local group for people with intellectual disabilities) “are gonny start working on a wee drama now...about keeping safe in the local community, so any new community initiatives, if I can support it with our guys (I will)” (Support worker for an individual with an intellectual disability).

“it’s about having safer communities, so having an approach that as communities we’re aware. There’s these initiatives going on but it’s all under the same umbrella; it’s to make everybody feel safe in their local communities” (Support worker for an individual with an intellectual disability).

As noted by Hall [63], community involvement is one aspect of social inclusion that enhances the quality of life of people with intellectual disabilities. However, research indicates that integration requires a collaborative effort: the individual with the additional needs must adapt to the community, but the community also needs to be responsive to their needs [19]. The Scottish Commission for Learning Disability [64] highlights a similar point, in that individuals supporting people with intellectual disabilities into mainstream community groups will help them to adapt to the group, and vice versa. Existing research also indicates that successful participation is characterised by equality in that the individual with an intellectual disability feels and is perceived as an equal and full member of the group—as discussed in the previous theme—and is engaged in a high degree of co-operative working within the group [24]. Research has also demonstrated that disabled people do not always wish to be associated with other disabled people [65], however, contrasting work has shown that disabled individuals can feel a greater sense of belonging when around others also like them, and that spending time in places that feel safe is a key element for the maintenance of friendships between disabled people [66], as detailed below in the next theme.

3.4. *Feeling Safe*

One striking finding that was clear from the people we spoke to was that feeling safe is often dependent on other people. Indeed, Gerber [67] reviewed the different factors that can contribute positively to quality of life for people with intellectual disabilities and for successful adjustment in the community and identified the important role that peers and family play in offering social support. Consider the following:

(when asked if she thinks her mother feels safe) “I think so because there’s neighbours that look out for her curtains aren’t open, you know, so, knocking the door” (Carer of an individual with Dementia).

“We are lucky, when we’re out and about, people help” (Support worker for an individual with an intellectual disability).

(Talking about her sheltered accommodation) “you’ve got people looking after you...a perfect place” (Person with Dementia).

Above, we see the participant discuss how her assurances of her mother’s safety comes from her mother’s neighbours who will check in with her mother if anything seems out of the ordinary (i.e., her curtains not being open). Similarly, another participant talks about feeling “lucky” due to other people helping when they are out in the community, whilst a person with dementia talks about the security she feels from the people looking after her. Research has similarly identified the importance of strong commitment by community members to support more vulnerable individuals in rural places [68]; indeed, this focus on support is mentioned as one of the defining features of a dementia-friendly community by Alzheimer’s Society [69], but returning to the focus on isolation, consider the individuals who are not able to contribute to the community, as detailed in the following quote:

“I also think as well that those that are socially isolated: do we know we are connecting with them? I’m very conscious in terms of community engagement that I see a lot of people—a lot of people—and there’s a real will to join in things, but I see a lot of the same people and they’re doing shed loads of work but I worry that the people I don’t see—who am I not seeing?” (Community Stakeholder).

A key finding from existing research is the importance of support staff/carers for individuals with an intellectual disability and those with dementia (e.g., [19,70]): this is absolutely crucial, as without support and care, some individuals with an intellectual disability and/or dementia would

face considerable difficulties with many routine daily activities, as well as participating in the community [71].

Shalock et al. [72] identified the twenty-five most commonly reported indicators of quality of life which include community integration and participation, community roles and social supports: it is evident from the data set that without support from others, individuals with dementia and intellectual disabilities would be even more isolated than they currently are. In this, they are no different from any other member of society, for all that the nature of that support may differ in terms of scale and intensity. Indeed, the increasing profile attached to isolation issues within Government policy [18,73] further highlights the basic need for connection that all community members share.

3.5. Supporting Community Participation

Community members also identified a range of enablers that may facilitate increased community participation. The enablers identified mostly related to support, either physical in the form of improved transport, more accessible information and having someone available to assist and provide both practical and emotional support. For example, the issue of accessing transport to enable individuals to participate in a wider range of community events was discussed at length, particularly as access to transport was currently perceived as a constraint. For example:

“She stays in a little village eight miles out of town, there’s a lot less opportunities there, and because transport becomes a logistics thing” (Carer of an individual with Dementia).

“I think it’s transport we need—better transport” (Carer of an individual with Dementia).

The above quotes are just a sample of the responses concerning how the lack of transport can act as barrier, but improved transport can function as an enabler. This is in keeping with existing research which highlights the significance of transport as an enabler to community participation [74]. Although there may be opportunities for vulnerable individuals to contribute to community activities, if they cannot physically get there, then the opportunity cannot be maximised. It is important to remember that the simple practical availability of transport may not be sufficient, and individuals may require support to use transport due to cognitive difficulties, money troubles, or low confidence [75].

Another facet of “support” is the enabling aspect of being able to access information. Participants in this study clearly reflected on existing practice and highlighted the need for information about community happenings to be delivered in a way that is accessible to all. The fact that there is variability in how people share and receive information was also noted and the importance of recognising these individual differences to minimise the risk of marginalisation for all vulnerable groups [20]. For instance,

“I don’t know that we always present information in the best way for people” (Support worker for an individual with an intellectual disability).

“The communication needs to be put out in different ways so that everybody knows...Facebook will get one generation, newspapers will get another generation but you’re not going to get your person with dementia who’s stuck in the house on a Facebook page or reading the local paper, so you’re not—to me it’s just simple: you’re not going to get them” (Support worker for an individual with an intellectual disability).

When discussing the issue of community inclusion consideration was given to the importance of raising awareness within the wider population of the needs of individuals with dementia and a learning disability in order to foster increased inclusion within the community, as evidenced by the following:

“I think as an area we need to maybe raise a bit more awareness among young people” (Community Stakeholder).

(The community needs) “to be more caring, considerate, and I think people’ve got to learn what it’s all about, and understand it a bit more” (Carer of an individual with Dementia).

The importance of awareness is recognized as being crucial for the community inclusion of individuals with dementia [31]. However, awareness although it may be necessary may not be sufficient. For example, in relation to people with an intellectual disability as research indicates that integration for people with a learning disability requires a collaborative effort: the individual with a learning disability needs to adapt to the community, but the community also need to be responsive to their needs [19]. Interestingly this was recognised by respondents who also identified that not only was community effort and awareness required, but also that people with dementia and a learning disability need to be aware of the community happenings:

“Is there a better way of advertising what there is for people? I don’t know how you target the folk individually, but how do we make sure people are getting the information about what we’re saying?” (Support worker for an individual with an intellectual disability).

“Even letting people know that’s on and things: it doesn’t matter how many posters you put up, it’s sometimes difficult to make contact with everybody” (Community Group Leader).

Participants also recognized the need to provide more opportunities for participation with the very practical suggestions of facilitating more scope for involvement not just for vulnerable individuals but for the whole community, whether that be through work placements, buddies to go shopping with, or community events, offer interesting ways to break down these barriers. For example:

“I think more opportunities for them to be involved in their communities, whether it’s volunteering, whether it’s wee work placements. Just being able to be involved in initiatives if there’s clubs, if there’s activities going on” (Support worker for an individual with an intellectual disability).

“I was suggesting like a buddy system in supermarkets/a befriender, a buddy, and transport to get to places” (Support worker for an individual with an intellectual disability).

“For our group of people, anything arts and crafts and anything music...even if they could do something like all year round, like even set up a tea dance almost, so it was open to everybody, not just our focus” (Support worker for an individual with an intellectual disability).

“I’m sure there was a lot of more things that they could add to the town that’s already here to help other people and I just feel there’s a definite lack of further thinking” (Carer of an individual with Dementia).

Participants recognized that there is a clear gap between the kinds of opportunities that are sought, and the ability to put them in place. It is essential that this area is addressed as research demonstrates that participating in leisure activities has benefits beyond those associated with remaining physically active but also promotes social and mental well-being [70].

Existing research illustrates the important role of support staff and carers in enabling the community participation for individuals with a learning disability and those with dementia [19] and their importance was also recognised and valued by participants in this study:

“You can’t just put ten people with a learning disability in a room and expect them all to learn the same way as you or I; they need support” (Support worker for an individual with an intellectual disability).

4. Discussion

The project findings highlight a range of psychological factors and practical influences on the safety and community participation of people with intellectual disabilities and/or dementia. Stigma and lack of awareness within the community presented significant barriers, which are by no means unique to the populations considered here, but which carry further significance as a result of their particular vulnerability and potentially considerable support needs. As an enabler and consequence of community participation, self-worth has a significant contribution to make to the overall wellbeing of individuals. Yet as highlighted here, its absence can present a significant barrier to that participation, and increase the risk of social isolation within the community. This was a very real issue for participants within the project, which further highlights the importance of the crucial role played by support from others in generating feelings of safety and enabling participation.

Responses to this complex interplay of issues are varied, but a particular approach highlighted by participants within this study was the promotion of “Keep Safe” schemes. These community initiatives work with a network of businesses such as shops, libraries and cafes who have agreed to make their premises a Keep Safe place for people to go if they feel frightened, distressed or are the victim of crime when out in the community. Keep Safe places are identified by displaying a sticker in the premises’ window and are listed online [76]. Research has demonstrated that people with an intellectual disability often report observing the community instead of being part of it [77], and so such initiatives allow individuals to engage with the community, and also have the safety net of certain places they can go if they feel vulnerable. Similarly, research has identified that at some point in their disease process, people with dementia will have a “missing” incident and be unable to safely return to their care setting [78], at which point having established and identifiable places of safety to go to will be of the utmost importance. Participants in the current study identified the potential value of Keep Safe locations within their community. A recent report reviewing the Keep Safe initiative identified that, of 660 responses from a wider community survey, 94% thought that the Keep Safe initiative was worthwhile; 84% highlighted that it had made them more aware of disability hate crime and harassment; and 82% were more likely to report incidents of suspected hate crime [79]. Recent research has also explored the concept of “self-building safe havens”, demonstrating that individuals with intellectual disabilities are themselves finding and negotiating welcome spaces in their neighbourhoods, and reclaiming the welcoming communities’ agenda [80].

While “Keep Safe” schemes definitely have much to offer as regards further enabling community participation, the multi-faceted perspective highlighted previously encourages the exploration of other routes. The promotion of “Keep Safe” schemes are welcome steps towards addressing some of the barriers discussed here, yet they remain partial solutions delivered in ways which acknowledge and are limited by the status quo, for example, in being inherently risk oriented approaches.

The findings from this study offer a more positive means of conceptualizing and promoting inclusion, with a number of participants discussing how sensitivity and awareness of needs of vulnerable individuals contributes to feelings of actual and perceived safety. For example, one participant spoke about people being helpful when they were “out and about”; another participant discussed the benefits of a vulnerable relative having neighbours who would look out for them, and another participant spoke about the need for the community to be “more caring, considerate”. The recognition of helping and caring as factors in facilitating safety and inclusion opens up the opportunity to consider the role of kindness, at the individual and community level. The multi-faceted perspective on inclusion introduced previously can apply here as: Knafo-Noam et al. (2015) describe how the complex array of positive behaviours displayed by humans, which they refer to as “prosociality”, encompasses behavioural, attitudinal and emotional elements [81]. As well

as reflecting this conceptual link, a focus on kindness also provides a practical link into current activity regarding community and service development.

Kindness as a concept invites a variety of definitions and approaches to describing and measuring it are still evolving [82]. There is, however, a growing body of evidence outlining the positive impact of acts of kindness at an individual level, to the extent of describing the neurological changes associated with their commitment [83]. While there has been recognition of a need for kindness to figure more explicitly in public policy [84], the related concept of compassion has an established place both as a potential mechanism for improving professional practice [85,86], and as a tool for change promoted in policy (for example, within the Compassion in Practice vision and strategy document produced by the English Department of Health (2012) [87], and the Compassionate Connections learning resources produced by NHS Education Scotland [88]). The notion of kindness as a relevant focus of explicit consideration is also increasingly emergent, linked not only to research based enquiry such as that outlined previously, but also high profile, practical examples of community change, such as the various strands of activity taking place as part of the Compassionate Inverclyde programme [89] which focuses on what the authors describe as “enabling ordinary people to do ordinary things for ordinary people” [89, p2]. This includes the provision of conversation cafes, the provision of boxes of food stuffs and other resources for people coming home from hospital and the delivery of a programme of support to school pupils and others exploring the benefits of being kind to yourself and others.

Recent work by the Carnegie Foundation [90] further highlights the potential of kindness as an alternative perspective on risk and inclusion; one which is broader in its vision and has clear links to the psychological dimensions of community safety and participation—stigma, self-worth, and isolation—highlighted by this study. The Carnegie Foundation examined the place of kindness within communities, how it is realized, and how it can be promoted, and highlighted a range of barriers to kindness, including concerns about personal risk (what will happen when we open up and interact with others); regulation (the focus of organizations of managing risk through policy and regulation); professionalism (the perceived dominance of the “dispassionate professional” ideal); and performance management (measuring what we can, as opposed to what matters). The response of the Carnegie Foundation to these barriers [90] included leaders and government empowering people to act in kindness, and making it easier to do. Crucially, they also speak about the need to think and talk about kindness, with the consequence that this in itself will encourage kinder action.

The work of the Carnegie Foundation and others, combined with the existing evidence base around kindness and prosocial behaviour more generally, provides a significant conceptual and practical resource for further exploring the role of kindness with regard to inclusion. As suggested by the responses of participants within the project described here, there is a clear link between concerns about kindness within communities, and issues of safety and inclusion with regard to marginalized populations. This is particularly true when viewed in light of the psychological aspects of safety and community participation highlighted within the current work, and the role of issues such as confidence and self-worth as enablers for inclusion.

A potential obstacle to the adoption of kindness as a focus for community development may be that how this can be achieved is perhaps less readily tangible than actions linked to notions of risk (such as the promotion of “Keep Safe” schemes). Yet, as a long-term destination, guiding development of inclusively designed services and communities, greater kindness seems to be an aspiration worth investing in. While the promotion of kindness in a community and service context is inherently positive, the responses of participants within the work described here highlights the need to retain sight of marginalized groups such as those with intellectual disabilities and dementia while doing so. Indeed, the current authors would argue that basing any such activity around a consideration of those groups in the first place, should be a priority.

A kindness-oriented approach to the development of inclusive communities has a further advantage in providing a unifying framework for considering all members of the community. As noted earlier, vulnerable individuals (regardless of source e.g., dementia or an intellectual disability) seem to encounter similar challenges to safety when engaging in the community, and it may be

beneficial to adopt a more global approach that seeks to accommodate the needs of all, as opposed to developing specific responses to the needs of specific groups of individuals. Communities should be more inclusive in general and thereby be able to meet the needs of all members. The dementia-friendly communities movement has a profile and momentum which has the potential to benefit many, if it is developed with deliberate attention being paid to its potential for cross-cutting benefits. The same holds true in relation to work focused on people with intellectual disabilities. As noted in the previously cited work from the Scottish Commission for Learning Disability [64] (pp. 6) “if the learning disability movement joined with other movements to advocate for a place-based approach across Scotland, the impact would be transformational”. Arguably, it is in the promotion of this synergy that the greatest potential lies for addressing community safety issues in a way which will benefit a range of marginalized groups.

A further mechanism for facilitating that synergy, which draws in both physical and psychological aspects of community participation, is the Inclusive Design paradigm. Inclusive Design (or the similar label, Design for all) provides an existing option which encourages the exploration of design issues with a view to accommodating a broad range of needs and abilities. The British Design Council describes Inclusive Design as aiming to remove of barriers that create undue effort and separation, thereby enabling everyone to participate equally, confidently and independently in everyday activities [91]. As such, it has much to offer in terms of enabling individuals, thereby building self-worth, which, as highlighted by the present study, is a critical resource in respect to safety concerns and community participation. While the project around which the present article is built identified a significant crossover with regard to the concerns of and barriers experienced by people with intellectual disabilities, and those with dementia (e.g., transport access; the experience of stigma; lack of accessible information on community opportunities; lack of awareness within the community), as the above quote suggests, it is in a broader vision that the most potential for progress may lie. Inclusive Design has the potential to accommodate that breadth of vision.

Inclusive Design is a clear priority within the private sector, but the extent to which it is consistently and meaningfully realized within the broader community and public sector is debatable. Collaboration with the community as part of the work described here highlighted the potential in creating new opportunities for engagement and exposure, to overcome prevalent preconceptions, and build greater confidence in marginalized groups. It may be that a critical part of this exposure/engagement relates to those specialist services supporting groups such as people with intellectual disabilities, or dementia. Professional identity is a powerful motivator for all, and for those working within specialist services, that professional identity is frequently closely tied to the identity of the individuals they work with, as perceived by the service. Inclusive, safe communities demand a lowering of barriers and divisions, yet all too often, services seem to be built around the preservation of some of those divisions.

Although it is anticipated that the conceptual frameworks for increasing community participation and the research findings discussed, with their emphasis on considering both the practical and psychological determinants of safe community participation, will promote debate, discussion, and help inform interventions; it is also essential to recognize the limitations of the current study. The small scale exploratory nature of this study entails some methodological implications that should be noted. The study was conducted in close collaboration with a community group who wished to make their community more inclusive and the study drew on these community links to facilitate recruitment. Doing so may have induced a degree of bias into the sample with participants potentially having favourable attitudes towards inclusion. However, this also brings the advantage of an informed perspective and the data itself shows how participants were able to critically reflect on existing initiatives and identify improvements for the future. The recruitment of vulnerable participants also presented a challenge to the research team and the final number of individuals interviewed was lower than anticipated. This may be attributable to a number of practical (not aware about the option to participate or lack of support to allow participation) and psychological factors (low self-esteem and/or not viewing themselves as a

member of the community) many of which are a consequence of poor community integration in its own right. It is interesting to note that such factors were identified as barriers to inclusion by participants, with and without disabilities, within this study; and difficulties in engaging and recruiting individuals who are excluded or those of high risk of exclusion is a well-recognised challenge [92]. In order to maximise the voice of vulnerable individuals future research would benefit from supporting the interview process by the use of symbolic/photographic material and draw upon a “Talking Mats” approach where needed, to guide participants through the interview process at their pace and provide a supportive structure for their responding [93,94]. The provision of practical support, in terms of self-advocacy training, to help vulnerable participants articulate their views may also be beneficial [95]. Future research may also benefit from the use of a mixed methods approach that draws upon observational work of actual community activities to supplement interview and/or questionnaire data and build a more contextualized understanding of experiences of all community members [96].

5. Conclusions

Community participation has clear benefits at an individual and group level, yet these benefits are not equally available to all. Our findings indicate that similar barriers to safe community participation are experienced by individuals with an intellectual disability and dementia alike. Furthermore, the research findings indicate the importance of considering the role of psychological determinants such as prejudiced attitudes and stigma, self-worth and feelings of community belonging in relation to community safety and inclusion. As the current project outlined, people with intellectual disabilities and/or dementia are significantly disadvantaged in this respect, with concerns about safety (in various aspects) contributing largely to this. Individuals and communities can potentially benefit from targeted activity (e.g., Dementia Friendly Communities) or risk-oriented approaches (e.g., Keep Safe schemes). However, a perspective on participation and safety which draws in psychological as well as physical concerns creates an opportunity to address these issues from other, possibly more positive and inclusive perspectives. The role of kindness and inclusive design within communities are two such perspectives. Arguably, how they can be leveraged as mechanisms for promoting inclusion and participation for all, particularly for vulnerable groups such as those with intellectual disabilities and/or dementia, is an area that has been significantly under explored to date. Doing so has the potential to bridge the areas of community safety and asset-based community development, to the advantage of all community members.

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