Voting and the Scottish Referendum – Perspectives of People with Intellectual Disabilities¹ and their Family- and Paid-carers.

Abstract

Voting is a human right for every citizen yet many people with intellectual disabilities do not vote or have little support to exercise their right to vote. This paper explores views on the wider aspects of voting against the backdrop of the Scottish referendum using focus groups with people with intellectual disabilities (n=12), family-carers (n=7) and paid-carers (n=5). Findings revealed that people with intellectual disabilities had similar concerns as the general population about the referendum. Regarding voting, all groups identified the need to discuss issues and for practical support and accessible information to ensure informed choices were made when voting.

Key words focus groups, people with intellectual disability, voting, family-carers, paid-carers

Introduction

In the United Kingdom (UK) registering the right to vote commences at 16 or over; however, no citizen is able to vote until they are 18^2 . In order to vote, the person must be 'British or qualify as a Commonwealth citizen or citizens of the Republic of Ireland or other European Union (EU) member states' (Electoral Commission 2015 np). Opportunities to vote differ for each of these groups, however, citizens of all countries comprising the UK are entitled to participate in the Westminster, European and local elections. The devolved nations also have their own elections for the Welsh Assembly and the Scottish Parliament. Eligibility to vote differs depending on the type of election taking place. ³

The act of voting can be undertaken in three ways: voting in person, whereby by the person physically goes to the polling station; by post, whereby arrangements are

¹ I have used the term 'intellectual disability' throughout this paper since it is the universal term rather than learning disability (a UK term) which although preferred by people with learning disability in Britain can cause confusion in the rest of the world as it can be taken to mean dyslexia.

² 16 year olds were given the vote in the Scottish referendum (where the Scottish people voted against independence from the rest of the UK). The Scottish government is looking at reducing voting age to 16 years across the electoral process.

³ Further information can be found on the Electoral Commission website (2015).

made to have a postal vote which is sent through the post; or by proxy. Here a nominated person can vote on the person's behalf but they have to be authorized by the electoral registration officer to do so (Electoral Commission 2015).

There is limited work on voting in people with intellectual disability but British research suggests that only around one third exercise their right to vote (and the figure is lower still in those with severe/profound intellectual disabilities). This is lower than in the general population (Emerson and Hatton, 2008; Mencap 2015). In the British general election of 2001, turnout was reported as 31% for adults with intellectual disabilities compared to 72% in the general population (Emerson et al. 2005), although the latter figure have been seen to be inflated (Redley 2008). Work undertaken in Cambridgeshire during the 2005 general election confirmed poor voting up-take by people with intellectual disabilities, finding that over 80% of this group had not voted compared to 39% in the general population (Keeley et al. 2008). Moreover, this study reported that only 66% of people with intellectual disabilities compared to 95% of the general population were registered to vote. This was surprising since there were initiatives to increase the number of voters from this group (Department of Health (DoH) 2001; Scottish Executive 2001). Scandinavian work on voting up-take reflects the situation depicted in the British data. For example, in the Swedish elections of 1994 and 1998, between 80 and 86% of the general population voted compared with 20 and 31% of people with intellectual disabilities respectively (Umb-Carlsson and Sonnander 2005; Kjellberg 2002).

Lower levels of voting in people with intellectual disabilities reflect the voting patterns in the homeless, inpatients and elderly, meaning that these groups have no say in determining who will govern the country and have no assurance that their concerns and specific needs will be heeded (Bosquet *et al.* 2009; Postle and Beresford 2007). Reasons identified for their low level of participation include inaccessible polling stations, literacy in terms of understanding the voting papers, comprehension of campaign issues, difficulties in registering to vote or not being registered and lack of a supporter to assist in voting as well as restrictive criteria about for who can and cannot provide such assistance (Bell, McKay and Phillips 2001; Redley 2012; Redley 2008; Electoral Commission 2015, Mencap 2015). Accessing polling stations may become more difficult in the UK due to cuts in local authority budgets. Although it has

been found that when postal voting was the only means of voting-participation increased (Bell, McKay and Phillips (2001), it is UK public policy that all citizens should be given the option to vote either in person or by post.

Factors increasing the likelihood of being registered to vote and actually voting include residing in supported accommodation rather than the family home and living with an active voter (Keeley et al. 2008). These findings are perhaps unsurprising since people with intellectual disabilities have rarely been empowered to make choices (Swain, French, and Cameron 2003). In the Scottish Government document *Keys to Life*, (a strategy to improve the lives of people with intellectual disability) political activity and voting is covered in 'Recommendation Two' and forms an essential part of the overall goal of social inclusion (Scottish Government 2013; McConkey 2007; Burchardt, Le Grand and Piachaud, 2002). Although legislation now provides greater opportunity for people with intellectual disabilities to take their own decisions, the literature raises a number of issues in relation to voting.

One issue pertinent to people with intellectual disability is that of capacity. In the UK the Electoral Commission (2015) states that a person cannot be refused a vote on the basis of 'physical or mental incapacity'. It is worth noting that across the 27 countries making up the European Union only six (including the UK) have no restrictions on the right to vote by people with intellectual disabilities (European Union Agency for Fundamental Rights 2010). The UK's membership of this group was a consequence of the introduction of the Equality Act (2010) which made it illegal to discriminate on grounds of disability. In the UK people with intellectual disability can only be refused a vote if they are not on the electoral register (Mencap 2015). It is acknowledged that decision-making and evaluating strengths and weaknesses can be difficult for people with intellectual disability because of the additional challenges they face with processing and retaining information (Goldsmith, Skirton and Webb 2008; Dye, Hare and Hendy 2007; Keywood, Fovargue and Flynn 1999). The problems raised here are similar to those associated with giving consent, in that people with intellectual disabilities could potentially mark the ballot paper without really knowing what they are voting for (Dye, Hare and Hendy 2007; McCarthy 1998). However, it could be argued that this is in principle no different from a voter

without an intellectual disability who may be completely lacking in political knowledge and information.

Similarly arguments for only allowing an educated electorate to vote have sometimes been put forward due to fear of 'sub-optimal political outcomes' (Redley 2012; United National Human Rights Committee 1996). This principle has not been enforced because it might exclude certain sections of the population and violate equalities legislation in some countries. It also raises questions about how informed a citizen would need to be in order to vote and how this would be assessed. Bell and Horsler (2003) advocated more education on citizenship for people with intellectual disabilities and those who support them. More broadly, research has identified prejudice about the ability of people with intellectual disabilities to vote or about them having a right to vote within the general public and support workers (Raley 2012, Bell, McKay and Phillips 2001). To reduce concerns, more awareness about the entitlement of people with intellectual disabilities to vote is needed for carers and the general public (Wilkinson and McGill 2009). It should be noted that in Scotland the new 'Curriculum for Excellence' requires that education about citizenship, including teaching about democracy, is given to all children from 3-18 years of age (Education Scotland 2016). This should ensure that a younger generation, both with and without intellectual disability, are more informed about voting and electoral participation, although no literature was found as to whether this had increased understanding of voting or citizenship in young people with intellectual disabilities.

The social model of disability sees disability as a difference and highlights the lack of opportunity and barriers within society rather than the medical model which sees disability as a deficiency (Martin 2003). Navigating the voting system is one such obstacle. In order to vote, a person needs to be registered and for someone with an intellectual disability this often requires practical support. Proxy voting, for example, requires specific registration as well as finding someone over 18 years of age who is eligible to vote (such as a family member or a paid-carer) to cast the proxy vote. Negotiating this process means that the person with intellectual disability must know about it beforehand and that a person has been identified who is willing to assist them. That 'supporter' has to sign a declaration to the effect that they are fulfilling that role. Under current rules, a paid-carer can only cast a proxy vote for a

maximum of two people in any single election meaning that some people with intellectual disabilities living in communal homes may be unable to vote due to a lack of eligible supporters (Electoral Commission 2015). Another potential problem arises from the introduction of individual electoral registration in 2014. This places the onus of registering to vote on the individual rather than on one nominal person in a household registering every eligible voter within it. This may present problems for people with intellectual disabilities, especially those living in the community with minimal assistance, since much of the procedure is undertaken on-line.

Although carers can lend support, the literature suggests that paid-carers have often been unaware or unsure of voting rights, with some staff fearful of influencing the voting choice of vulnerable groups and thus opening themselves to potential accusations of electoral fraud or vote rigging (Humphreys and Chiswick 1993; Smith and Humphreys 1997; Regan Hudson and McRory 2011). Other groups such as the elderly or Asian communities have been identified as potential targets for electoral fraud (Electoral Commission 2014), although this is an issue for all vulnerable groups, including people with intellectual disabilities (Antaki *et al.* 2008;BBC News 2005; Rodgers, 1999; Humphreys and Chiswick 1993). In order to reduce such anxieties and facilitate voting by people with intellectual disabilities, both paid- and family-carers may require support in order to assist someone to vote (Llewellyn, McConnell and Bye 1998; Bell, McKay and Phillips 2001).

To ensure that people with intellectual disabilities are informed about their voting rights, it is necessary that they receive information in different formats tailored to their needs. However this information is either often not available or else considered to be the same as that for those with physical disabilities (Keeley et al. 2008; Redley (2012). In order to address disparities in voting participation, the Electoral Commission (2003) recommended that more resources should be made available for people with intellectual disability. This has resulted in an in increase in the availability of such materials; for example, on the commissions' webpage or published by voluntary/third sector organisations such as Mencap and ENABLE. However, during the Scottish referendum it was noted that the 'easy read' version of the Scottish Government's White Paper on Scotland's Future (Scottish Government 2014a) was produced some five months after the original document.

In the light of the issues reviewed above, this paper examines voting by people with intellectual disabilities in the context of the 2014 Scottish referendum, an event previously not addressed in the literature. It specifically explores the role of family and paid-carers in supporting people with intellectual disabilities to vote, reviews what information they had received about the referendum and compares their attitudes to Scottish independence with those of the population as a whole.

Methods

Setting:

The study was conducted in one area in the West of Scotland between July and August 2014. All focus groups were conducted in a neutral space provided by a third sector organization. The organization was approached because it undertook work within a large area of Central Western Belt of Scotland and the authors already had links with its staff.

Participants:

Convenience sampling was used to recruit three groups of subjects: people with intellectual disability, paid-carers and family-carers. Unexpectedly, a number of people with intellectual disabilities, family and paid-carers recruited encouraged their friends/colleagues to participate, and so a snowballing effect also occurred. This type of sampling limits the scope of participants in terms of demographic range and size but ensures participants are well-placed to provide data relevant to the research questions (Parahoo 2006). The third sector organization identified a member of staff who worked with the authors to identify potential participants. Recruitment of people with intellectual disabilities and family-carers was undertaken by the authors who were invited by the gatekeeper to present details of the study to potential participants at two regular group meetings convened by the third sector organization specifically for people with intellectual disabilities and family-carers. Recruitment of paid-carers was undertaken by the gatekeeper who contacted home managers connected with the third sector organization and sent out the participant information sheets. Potential volunteers were asked to get in touch with the gatekeeper and names and contact details were passed on to the authors. Inclusion criteria for all groups were that

participants had to be aged 18 or over. All participants with intellectual disability had to have capacity (which was confirmed by the gatekeeper and one author trained in assessing capacity). Participants who had not voted or had not supported people with intellectual disabilities to vote were also included. This was because the researchers wanted to gain a range of views. In total 24 participants took part in the focus groups. Absolute numbers of potential participants approached were not given by the gatekeeper. On completion all participants were given a £10 voucher. While this approach proved to be an efficient and convenient method of gathering the sample for this study, its limitations are addressed in the later discussion.

Focus groups:

Focus groups were employed because they allowed participants to share and discuss similar experiences (Bryman 2010). Evaluation of focus groups as a means of data collection for people with intellectual disability has affirmed their utility (Gates and Wright 2007). Separate focus groups were conducted with people with intellectual disabilities, family-carers and paid-carers because this enabled more in-depth discussion of ideas to take place and also avoided any power imbalance (e.g. carers/client, parent/child, paid-carer/parent). They were held at times, dates and places convenient for the groups. For people with intellectual disability and the family-carers, they tended to run in parallel to the organization's usual group meeting to allow continuity of social activities. For the paid-carers, the focus group was a chance to enhance social interaction within their paid role.

Ethical approval and consent:

All participants received written and verbal explanations about the study (suitably adapted for those with intellectual disabilities) prior to agreeing to participate. Consent was taken on the day of the focus group and for the paid- and family-carers written consent was required. For people with intellectual disabilities, an adapted consent form was developed. Each participant had this explained to them by one of the authors or by their own carer if they had escorted them, and they were asked to give either verbal or written consent. Prior to taking consent, all participants were asked if they had any questions; they were reminded again that participation was voluntary and that they could withdraw at any time. It was reiterated that the focus group would be tape recorded, that all information would remain confidential and if

used in any publications would be anonymized. Ethical approval was obtained from the University Ethics Committee.

Discussion guide:

A focus group discussion guide was developed from findings identified within the literature and from questions posed in referendum campaign material. The authors had also attended a workshop about the referendum for people with intellectual disability organized by the Learning Disability Alliance Scotland (LDAS) which informed their choice of issues. Topics from previous focus groups were also incorporated, such as whether it was thought that the views of people with intellectual disabilities were different from those of the general population. Although the discussion guide was similar for all three groups in terms of asking what the referendum was about and what it meant to them, questions differed in their focus. Questions to family- and paid-carers concentrated more on whether they had supported a person with intellectual disability to vote and how they might explain the voting process and the referendum issues to someone with an intellectual disability, as well as their views on people with intellectual disability voting. Questions to people with intellectual disabilities explored what Scotland becoming independent might mean, any concerns they had about the prospect and whether they had previously voted.

Analysis:

All focus groups were audio-taped and transcription was undertaken contemporaneously, with analysis being concurrent with transcription. The data analysis framework developed in this study was based on the thematic framework of Smith and Osborn (2003). The transcripts were read and re-read by three of the authors until they were familiar with their content. At this stage notes were made in the margin of the transcripts about anything that the reader found significant in what the respondents were saying. This included jotting down emerging themes and key words to capture the meaning of the text. Each author then amalgamated their notes from each of the focus group to produce a list of themes that they believed reflected the essence of the discussions. Once this had been undertaken by each author, they

met to discuss similarities and connections. Any conflicts or differences were examined and resolution arrived at. This process enabled a master list of themes to be constructed which captured the respondents' concerns. These themes were then mapped back to the transcripts to ensure that they accurately reflected the prevailing idea of the participants. The themes were then validated by the remaining author. It was noted that within the focus groups some of the themes closely followed questions on the topic schedule. Trustworthiness of the findings was buttressed by each researcher undertaking independent analysis before coming together with their co-authors. The findings were also fed back to the groups lead by the remaining author as a further means of validating the findings. The themes were common to each focus group with the exception of how paid and family-carers would support the person to vote with intellectual disabilities.

Findings:

Three themes were reported: 'what are we voting for?' explored the issues raised by people with intellectual disability; 'who should I vote for?' explored the influences that might sway the vote of someone with an intellectual disability; and 'enhancing voting' looked at ways to support people with intellectual disability to vote. The themes form the structure of the discussion, but before discussing them in depth, we provide details about the final participants.

Demographic variables such as age were not asked for nor were the qualifications of the paid-carers. The focus groups comprised 12 people with intellectual disabilities (male= 3/female=9), seven family-carers (male= 2/female=5) and five paid-carers (all female) and were coded F⁴ID, FFC and FPC respectively. All of the focus groups were conducted by the first three authors and lasted between 45 and 90 minutes, depending on how much the participants wanted to contribute.

Family- and paid-carers supported people with a range of levels of intellectual disabilities. They believed that voting was a fundamental right and that it was the

⁴ F= Focus group, ID= intellectual disability, FC= Family-care, PC = paid-carer

responsibility of everyone (social workers, families and health practitioners) to support people with intellectual disabilities in voting. A minority of carers⁵ believed that not voting was wrong or that it should be mandatory for everyone.

The first theme, 'What are we voting for? explored the issues that people with intellectual disabilities raised in relation to voting and the referendum. Ten people with intellectual disabilities had voted before and were able to describe the voting process: voting in churches or schools or by post, and of going into a booth if voting in person. Most displayed good knowledge and understanding about politics and elections: for example, they were aware that in general or local elections they voted for a party and that Alex Salmond was First Minister of Scotland at the time. However, the voting age caused some confusion. When asked whether they would vote in the referendum all but two said they would and the majority of the group understood what the referendum was about:

'....if we want to go independent and no independent (Sam:FID).

Participants were not asked which way they would vote, but one participant posed a reason for voting yes:

'....one thing that we want to go independent, see when the English people said let's get council tax...They says Scotland can be our Guinea-pigs. (Lesley:FID).

Being Scottish was important to people with intellectual disabilities and they identified elements that Scotland was famous for, such as oil, whisky, the Commonwealth games, tartan and kilts. There was anxiety expressed about what would happen if Scotland gained independence, especially about defence:

'...Just say Scotland is independent for England and they couldn't handle Hitler's forces. Would they ask us for help? Or would we be asking for help.' (Lesley:FID)

⁵ Unless specified, the term 'carers' is used within the findings to denote both family and paid-carers in order to avoid repetition of the term 'family- and paid-carers' throughout the paper. When the two groups displayed differences, they have been referred to specifically.

'I don't like the nuclear weapons....I was frightened of nuclear weapons.' (Tina:FID)

'They says oh Scotland are allowed to keep its pound, they're, now saying... you're not allowed to.' (Lesley:FID)

One participant also asked whether there could be a trial separation. Others voiced concerns about television stations and what programmes would be available:

'BBC in Scotland so how can you have no EastEnders?' (Janice: FID)

The second theme, 'who should I vote for?', looked at the influences that people with intellectual disabilities might be exposed to. One of the main opinion-forming agencies identified was parents and it was clear that some people with intellectual disabilities were swayed by them:

'My mums always told me to vote Labour, right..... when I go to talk to her and [she] says to me always vote Labour, with common people.' (Alana:FID)

This last comment related the issue that some families allegedly believed that they had two votes:

'.....some parents that will tell you 'well I've got two votes cause I tell them what to vote' so that's two votes for the party.' (Julia:FFC)

Paid-carers also recognised this as a potential problem:

'There's the opportunity there for support workers that are maybe supporting three or four service users to go in and....tell all them to vote independence. (Roxy:FPC)

However, these influences were no different to those on many other people in society:

'....we listen to what our parents said in generationsand that's no different for people with intellectual disabilities.' (Rufus:FFC)

Despite this, all carers were aware of the guidance they could potentially exert:

'As a parent you've got to be very careful that you don't influence them to think your way of thinking.' (Sally:FFC)

Paid-carers perceived a duty to counteract such pressures:

'It definitely is in your job to challenge.' (Siobhan:FPC)

Other influential factors that were identified included the referendum literature that was distributed and the groups that the people with intellectual disabilities were involved in:

'Writing letters and putting them in your letter box.' (Howard:FID)

"She's been to the parliament several times and knows the MSPs who are interested in intellectual disability.....she calls Jackie [Baillie], Nicola Sturgeon her friends.' (Rufus:FFC)

Few participants in all the groups had seen the easy-read leaflet on the White Paper produced by the Scottish Government or Enable's booklet on the topic. Despite this, there was enthusiasm for a forum to help inform people with intellectual disabilities and carers about the political agenda:

'Not enough places to go and sit and listen to people...It's all about politicians telling you what they think......' (Frank:FID)

Nevertheless, members of all the groups wanted politicians to come and speak to them in their immediate community, both during and outside election periods. This discussion led on to the final theme, 'Enhancing voting', which explored how people with intellectual disabilities could be supported to make an informed choice. Most carers involved in this study had supported people with intellectual disability to vote and all the individuals they supported were registered on the electoral role. In terms of facilitating this, a number of issues were identified. One related to practicalities such as going into the polling booths, since some polling station officials appeared to be more helpful than others:

'Sometimes the staff at the voting booths will allow you to go and stand beside your son or your daughter. Others... they're not really keen you doing that.' (Sally:FFC)

Others also mentioned that having a postal vote meant that they could return the polling card if the person was unable to vote:

'They've got the choice there in front of them, they don't want to do it, they don't understand, it [the polling card] gets sent back and then...nobody else has used it' (Siobhan:FPC)

Carers reported that voting behaviour in people with intellectual disabilities was linked to the support the person received:

'A lot of people that are supported by organisations are in their own houses but they maybe get minimal ten hours support a week. I don't know how involved these support workers get with things like that [voting].'(Roxy:FPC)

Paid-carers also commented that voting might be ignored because it was not documented within people's care plans:

'.....I've never came across in the community anybody's support plan that they should be supported by voting.' (Tanya:FPC)

However all paid-carers believed this should be part of their role:

'....we do everything else and anything that you can think about a person's life, it's in their support plan, so I'm sitting here today thinking ah-hah that's something that should be incorporated.' (Tess:FPC)

To increase voting participation, carers believed they had a responsibility to access information and discuss this issue with people with intellectual disabilities, especially if the person had no regular support from service providers. Paid-carers raised the issue of training and support to facilitate this, as a minority of them felt they lacked sufficient knowledge about politics to support their client.

'I've chosen not to support purely because I don't have the greatest understanding myself. So I think that would be wrong of me to go out and support somebody to [do] it.'(Siobhan:FPC)

To ensure that people with intellectual disabilities were fully informed, easy-read information, DVDs and pictorial images to explain voting were seen as useful, while others suggested having specialists address groups:

'It might have been nice if there was a perfectly neutral individual that could [do this].' (Julia:FFC)

Other practical suggestions related to registering clients on the electoral roll and obtaining assistance to reach the polling station, circumventing literacy problems and enlarging the ballot paper to reduce spoilt votes due to people putting 'a cross anywhere'.

The final issue raised was capacity and voting. Both sets of carers acknowledged that some people with intellectual disabilities were not able to vote due to their lack of understanding, especially those with severe/profound intellectual disabilities.

'It's not something that I have felt that my daughter could reasonably be expected to understand.' (Rob:FFC)

'We have service users....I would say wouldn't have the capacity to understand even what a vote was.' (Fran:FPC)

For some it was difficult to determine who could or could not vote:

'I think it's very difficult but I mean, where do you draw the line and how do you divide people into those who can and can't [vote].' (Jodi:FFC)

Some family-carers suggested both chronological and mental age should be considered in terms of eligibility to vote. Generally, their concerns were about what people with intellectual disabilities thought they were voting for, with some noting that party political issues would not be understood:

'[it's] not on a vote, it's a game to 'name' because he's picking a name. He'll watch the entire night to see his man has won.' (Josie:FFC)

However, relating the content to the person was one way of helping them understand the issues:

'If you told her that one party was going to stop the youth group that would be a big influence on her. But it would need to relate to her own issues.' (Rufus:FFC)

Discussion

The number of people with intellectual disabilities who reported voting in previous elections was high in this study. However, this was a small-scale project, unlike previous work that reported on larger numbers and identified lower voting levels (Keeley *et al.* 2008). There is a dearth of literature about political knowledge in people with intellectual disabilities, and no research specifically about the Scottish referendum, which makes this study unique. In contrast to the findings of Bell and Horsler (2003), knowledge about voting and politics was generally good, with the exception of the confusion about voting age. This can be explained on the grounds

that, exceptionally, sixteen-year olds were permitted to vote in the Scottish referendum. Furthermore, the concerns expressed about health, defence, and the currency, were no different to those raised within the general population (McWhirter 2014). When the discussion about what soap operas might not continue after a vote for independence was fed back to the family-carers, one person expressed surprise that this reflected a general concern within the Scottish public. While some people with intellectual disabilities may not have the capacity to understand politics, this issue also reflected ignorance about political affairs among sections of the general population. Yet, in contrast to people with intellectual disabilities, the right of the politically ignorant to cast their vote is not questioned. This reinforces the point that people with intellectual disabilities are 'disabled by society'. It highlights the need to ensure they are treated as full and equal citizens and be given the opportunity to feel empowered to vote (Arah 2008, Bell and Horsler 2003).

Paid-carers saw voting as important. They believed it should be formalised within the person's care/life plan and was considered to be the responsibility of anyone who supports individuals with intellectual disability. In contrast to previous literature (Humphreys and Chiswick 1993; Smith and Humphreys 1997; Regan Hudson and McRory 2011), although in line with the findings of Bell and Horsler (2003), all carers were clearly aware of voting rights. Family-carers had also registered their off-spring, which contrasted with the earlier work of Keeley et al. (2008). Carers noted that their lack of knowledge about politics may inadvertently prevent the people whom they supported from making an informed decision or in some cases having a vote, which supports previous work on carers knowledge (Bell and Horsler 2003). Where knowledge or information was lacking, paid-carers in this study sought help from external sources such as the LDAS. Registering the person with intellectual disabilities to vote depended on someone supporting them to do so. However, 'support' within care services has been found to vary (Willis 2015) and hence more training may be needed. With the introduction of individual electoral registration in 2014 it will be of interest to monitor turnout in future elections, as much is undertaken on-line. In terms of the social model of disability, it represents a failure within society to consider the needs of this population in relation to registration. Despite this, the findings affirm that people with intellectual disabilities have an appetite for politics

(Kjellberg 2002) and wanted to vote. This reflected attitudes in the broader Scottish population, given that turnout in the referendum was extremely high at 86% (Scottish Government 2014b).

Similar issues to those raised in the literature about how to enhance voting were mooted by participants (Bell, McKay and Phillips 2001; Redley 2012; Redley 2008; Electoral Commission 2015, Mencap 2015). However new ideas ideas were proffered, such as having information delivered in a neutral format such as the meetings organized by the LDAS. This organization delivered 52 workshops on the referendum to over 700 people with intellectual disabilities around Scotland. It highlights the role that third/voluntary sector organizations can play in supporting people with intellectual disabilities to vote (Mencap 2015). Despite Bell and Horsler (2003) advocating over ten years ago that more appropriate information should be made, participants in this study identified a scarcity of accessible materials. The authors suggest that governments should make all information accessible and comprehensible for all sectors of the community. A more general plea was for politicians to engage more with people with intellectual disabilities to ascertain their concerns and those who supported them. These requests, and the delay in publishing the easy-read version of the White Paper on the referendum, suggest that recommendation 2 in Keys to Life (Scottish Government 2013) will take some time to be fulfilled.

Support available at the polling stations was found to be inconsistent, which contrasted with the support needs already in place for those with visual impairments (Electoral Commission 2015). This suggests that training for staff at polling stations to accommodate the needs of people with intellectual disabilities may be required.

Bell, McKay and Phillips (2001) advocate placing symbols alongside the candidates' names⁶, having larger voting slips to prevent the vote from being designated as spoilt if crosses were oversized was a useful proposal.

Difficulties at polling stations were a reason why many carers had converted clients to postal voting. Postal votes were also seen to circumvent the problems around not

⁶ the party logo alongside the name is the norm in Scotland

wanting to vote or not understanding what voting was (e.g. by those with severe/profound intellectual disabilities) as the ballot paper could be returned rather than the vote being spoilt. Bell, McKay and Phillips (2001) suggested that postal voting enabled people with intellectual disabilities to participate in voting on their own terms, removing the difficulties such as the need to travel or go to unfamiliar places. However, this may also raise issues around influencing the individual's vote or the vote being used as a second vote by unscrupulous carers.

As with previous work (Raley, 2012, Bell, McKay and Phillips 2001), the question of capacity was highlighted by some participants. Carers in this study acknowledged that their clients' understanding of the process of voting was polarized (Bell and Horsler 2003). Two family-carers believed that entitlement to vote should be determined by mental capacity, suggesting that this was why primary school children were not permitted to vote. Some family-carers felt conflicted, having fought to get people with intellectual disabilities their civic rights but now debating whether that person should lose their entitlement to vote on grounds of capacity. However, classes on democracy are now taught to all children in Scotland (Education Scotland (2016) and there is clear guidance in the UK about who can and cannot vote (Mencap 2015). Nevertheless, more training for those who support them and ongoing education about democracy may be needed for people with intellectual disabilities.

It must be borne in mind that there were significant limitations to this study. The small sample size taken from one area and one organization in the West of Scotland means that the findings do not provide a basis for general conclusions nor represent the views of all people with intellectual disabilities. Reasons for pursuing the methods chosen were due to time constraints relating to ethical permission and mandatory police checks to permit working with vulnerable groups. Convenience sampling was therefore selected because the authors had links with organization, although snowballing occurred unexpectedly. In terms of the representativeness of the sample, the area from which participants were drawn has one of the highest densities of population in the country and so the authors were confident of drawing a sample from a broad range of participants.

Despite the small scale of the sample, we identified a lack of information available to this population on this important issue. We therefore offer the following recommendations: firstly to ensure voting is part of the person with intellectual disabilities' civic experience. Secondly that manifesto information and government documents use appropriate plain English, thirdly that neutral advisers be available to assist discussion of political issues and extended to carers in order to facilitate voting in those they support and finally revising training for polling staff be undertaken.

Conclusion

Given that people with intellectual disabilities face many inequalities, it is essential that they have a voice in driving the political agenda towards a more inclusive and equal society. One way of achieving this is by exercising their right to vote. In this study there was a clear appetite for political engagement in people with intellectual disabilities. However, in order to stimulate political activity and engagement there needs to more consideration given to supplying timely, adapted materials in order to support this and to establishing appropriate forums in which issues can be discussed. Given that voting in this study was inextricably linked to the level of support received and the severity of the intellectual disability, it is important that the training needs for those who support people with intellectual disabilities is addressed. This may be difficult to implement with cuts in training budgets but it may be important to include more facilitative approaches that enable them to support the engagement by clients with the available information. Voting itself needs to be formalised within their care plans to reinforce the message that voting is a basic right and an essential element of independent living. Some additional means should also be found to ensure that the political needs of those who are unable to vote can be acknowledged, rather than them being merely seen as non-voters. Finally, this study was found to have increased the awareness of such issues among those carers working in the community, especially for third/voluntary sector organizations who inform and support people with intellectual disabilities. All credit must be given to their efforts because without them fewer people with intellectual disability would have been aware of the referendum or participated in its historic outcome.

References:

Antaki C., Finlay M., Walton C. and Pate L. 2008. Offering choice to people with an intellectual impairment: an interactional study. *Journal of Intellectual Disability Research* 52, no 12, 1165–75.

Arah, O.A. (2008) Effect of voting abstention and life course socioeconomic position on

self-reported health. Journal of Epidemiology and Community Health. 62. 8. 759-760.

BBC News 2005. Voting scandal mars UK election Available at http://news.bbc.co.uk/1/hi/uk/4410743.stm [Accessed May 2015]

Bell, D. and Horsler, K. (2003). The right to vote: Learning. Disability Practice, 6(6).30.

Bell D., McKay, C. and Phillips, K.J. 2001. Overcoming the barriers to voting experienced by people with learning disabilities. *British Journal of Learning Disabilities*, 29, 122–127.

Bosquet A, MeDJAckane A, Voitel-Warneke D. Vinceneux, P. Mahe, I. 2009. The vote of acute medical inpatients: a prospective study. *Journal of Aging andHealth.21*, 5.699-712.

Bryman, A., (2010). *Social research methods* (3rd edn). Oxford: Oxford University Press.

Burchardt T., Le Grand J. and Piachaud D. 2002. Degrees of exclusion: developing a dynamic multidimensional measure. In: *Understanding Social Exclusion* (eds J. Hills,

J. Le Grand and D. Piachaud), pp. 30-43 Oxford University Press, Oxford.

Department of Health. 2001. Valuing people: A new strategy for learning disability for the 21st century.

London: HMSO.

Dye, L., Hare, D.J., and Hendy, S., (2007). Capacity of people with Intellectual disabilities to consent to take part in a research study, *Journal of Applied Research in Intellectual Disabilities*. 20 (2), pp.168-174.

Education Scotland (2016) what is the Curriculum for Excellence available at http://www.educationscotland.gov.uk/learningandteaching/thecurriculum/whatiscurriculum/orexcellence/ [Accessed 2nd April 2016).

Electoral Commission for Scotland. 2003. Scottish elections 2003, the official report on the Scottish

Parliament and local government elections 1st May 2003. Edinburgh: The Stationary Office.

Electoral Commission 2015 http://www.electoralcommission.org.uk/ accessed May 2015.

Electoral Commission (2014) *Electoral Fraud in the UK: Final findings and recommendations*. UK Available at http://www.electoralcommission.org.uk/ data/assets/pdf_file/0008/164609/Electoral-fraud-review-final-report.pdf [Accessed 6th April 2016).

Emerson, E. and Hatton, C. 2008. People with Learning Disabilities in England. Centre for disability Research: Lancaster University

European Union Agency for Fundamental Rights (2010) *The Right to Political Participation of Persons with Mental Health Problems and Persons with Intellectual Disabilities*. FRA-European Union Agency for Fundamental Rights, Vienna.

Gates, R., and Wright, M., (2007). Reflections on conducting focus groups with people with learning disabilities, *Journal of Research in Nursing*. 12 (2), pp.111-126.

Humphreys, M. and Chiswick, D. 1993. Getting psychiatric patients to the polls in the 1992 General Election *Psychiatrie Bulletin* (1991), 17, 18-19

lan Hood 2014 Personal communication.

Keeley, H., M. Redley, I. Clare, L. Luke, and A. Holland. 2008. Participation in the 2005 general election by adult with intellectual disability. *Journal of Intellectual Disability Research* 52, no. 3:175–274.

Keywood K., Fovargue, S., and Flynn, M., (1999). Best practice?: health care decision making by, with and for adults with learning disabilities. Manchester: National Development Team.

Kjellberg, A. 2002. Being a citizen. Disability & Society 17, no. 2: 187–203.

Llewellyn, G. McConnell D. and Bye, R. 1998; Perception of Service Needs by Parents

With Intellectual Disability, Their Significant Others and Their Service Workers Research in Developmental Disabilities, 19, No. 3, pp. 245–260.

McCarthy M., (1998). Interviewing people with learning disabilities about sensitive topics: a discussion of ethical issues, *British Journal of Learning Disabilities*. 26(4), pp.140-145.

McConkey, R. (2007). Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. Journal of Intellectual Disability Research, 51 No 3, 201-217.

McWhirter, I. 2014 Disunited Kingdom: How Westminster Won a Referendum but Lost Scotland, Cargo Publishing, Glasgow

Martin, J. J (2013) Benefits and barriers to physical activity for individuals with disabilities: a social-relational model of disability perspective. *Disability & Rehabilitation*, 35(24), 2030-2037.

Mencap 2015 https://www.mencap.org.uk/ Accessed May 2015

Parahoo, K., (2006). *Nursing research: principles, process and issues* (2nd edn). Basingstoke: Palgrave.

Postle K., Beresford P. 2007. Capacity building and the re-conception of political participation: a role for social care workers? *British Journal of Social Work.* 37, no. 1. 143-158.

Redley, M. 2008. Citizens with learning disabilities and the right to vote, Disability & Society, 23:4, 375-384,

Redley, M., Maina, E., Keeling, A and Pattni, P. 2012. The voting rights of adults with intellectual disabilities: reflections on the arguments, and situation in Kenya and England and Wales. Journal of Intellectual Disability Research, 56 No 11, 1026-1035.

Regan, P., Hudson, N. and McRory, B. 2011. Patient participation in public elections: a literature review. Nursing Management, 17 no. 10, 32-36.

Rodgers, J., (1999). Trying to get it right: undertaking research involving people with learning disabilities, *Disability & Society*. 14 (4), pp.421-433.

Scottish Government (2014b) First Minister on the Referendum Outcome Available at: https://www.scotreferendum.com/2014/09/first-minister-on-referendum-outcome/ [accessed 20th April 2015)

Scottish Government (2014a) Scotland's Future: Your guide to an independent Scotland. Easy Read Summary. Edinburgh: Scottish Government.

Scottish Government (2014) Keys to life: Improving Quality of Life for People with Learning DisabilitiesEdinburgh: Scottish Government.

Scottish Executive (2001) Same as you? Edinburgh: Scottish Executive.

Goldsmith, L., Skirton, H. and Webb, C., (2008). Informed consent to healthcare interventions in people with learning disabilities – an integrative review, *Journal of Advanced Nursing*. 64 (6), pp.549-563.

Smith H. and Humphreys M. (1997) Changes in the law are necessary to allow patients detained under the Mental Health Act to vote. British Medical Journal, 315: 431.

Smith, J.A., and Osborn, M., (2003). Interpretive phenomenological analysis. In. Smith, J. A., (ed.), *Qualitative psychology: a practical guide to research methods*. London: SAGE, pp.51-80.

Swain, J., S. French, and C. Cameron. 2003. *Controversial issues in a disabling society.* Milton Keynes: Open University Press.

HMSO 2010. The Equality Act HMSO: London.

Umb-Carlsson, O. and Sonnander, K. 2005. Comparison of the Living Conditions of Adults with Intellectual Disabilities in a Swedish County and in the General Population. Journal of Policy and Practice in Intellectual Disabilities 2 no. 3/4 pp 240–248

United Nations 2006. Convention on the rights of persons with disabilities. Available online at: www.un.org/disabilities/convention [accessed 3 May 2015].

Wilkinson, P. and McGill, P. 2009. Representation of People with Intellectual Disabilities in a British Newspaper in 1983 and 2001. *Journal of Applied Research in Intellectual Disabilities*, 22, no.1 65–76