

Participation of Adults with Intellectual Disabilities in the UK 2015 General Election

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Introduction

The right of all United Kingdom citizens to participate in the renewal every five years of the UK Parliament is enshrined within the Representation of the People Acts (1983, 2000), the Human Rights Act (1989) and the Disability Discrimination Act (2005). The 56th Parliament of the UK was elected on 7 May 2015. The entitlement to register to participate in the 2015 General Election in the UK was determined by the Representation of the People Acts 1983 and 2000 (RPA 83/00), which established who can and cannot register to vote. Section 4 of RPA 83 and Section 1 of RPA 00 states that:

A person is entitled to be registered in the register of parliamentary electors for any constituency or part of a constituency if on the relevant date he –

- is resident in the constituency or that part of it;*
- is not subject to any legal incapacity to vote (age apart);*
- is either a qualifying Commonwealth citizen or a citizen of the Republic of Ireland; and*
- is of voting age.*

Whilst in UK law there is no mental capacity test in relation to the right to vote, adults with intellectual disabilities continue to experience discrimination, which results in disenfranchisement. Some research has been undertaken into democratic participation, however the body of literature is limited. A scoping review of the literature (Arksey & O'Malley 2005) was undertaken to answer the question, “What is known from this existing literature about the barriers and motivating factors which result in an observable effect on participation rates?” The scoping review identified 11 papers that considered the issues, only three of which were empirical studies. This indicates that there is potential to gain

deeper understanding of the issues through further research into practice. Charting the data collated during the review, a recurrent theme was identified of low levels of democratic participation on the part of adults with intellectual disabilities being framed as a proposition that people lacked the mental capacity to exercise their democratic rights (Beckman, 2007; Redley et al., 2012; Agran & Hughes, 2013).

‘Mental incapacity’ is defined in the Mental Capacity Act (2005) as a person who is unable to make a decision in relation to a matter because of an impairment or a disturbance in the functioning of the mind or brain, whether the impairment or disturbance is permanent or temporary. This is different to the reference to ‘legal incapacity’ in Section 4 of the Representation of the People Act (1983/2000). Where a person has been assessed as lacking the mental capacity to make the specific decision as to where they live, for example, this does not mean there is a legal incapacity to register to vote or to participate. Section 73 of the Electoral Administration Act (2006) abolished any legal rules regarding the incapacity of a person to vote because of their mental state. People who meet the registration criteria under the Representation of the People Act are eligible to vote in the UK regardless of their mental capacity.

The extent of disenfranchisement experienced in political and democratic processes by adults with intellectual disabilities is essentially a breach of fundamental human rights (Lord et al., 2014). Article 29 of the Convention on the Rights of Persons with Disabilities (CRPD) requires signatories to guarantee the same political rights and opportunities as non-disabled citizens. CRPD has been described as a ‘paradigm shift’ away from a welfare response to intellectual disability and towards a rights-based approach (Kayess & French, 2008; Stainton & Clare, 2012; Mittler 2015). As a signatory to the Convention, the Human Rights Act (1998) enacted the ECHR into UK law. To date there is limited empirical analysis of whether the CRPD has positively affected the lives of persons with intellectual disabilities in exercising their democratic rights (Mittler 2015).

There are pervasive factors that result in the continued under-representation in democratic processes by particular societal groups (Political and Constitutional Reform Committee, 2014). Democratic exclusion of adults with intellectual disabilities was observed as significant during the 2001 General Election; less than a third of people with an intellectual disability reported that they cast a vote (Emerson & Hatton, 2008), just over half the turnout rate of 59.4% for the general population (UK Political Info, 2016). Even this low rate of engagement

may be an over estimate of actual participation rates, given that it was based on a sample survey (Emerson et al., 2005). A study of participation in the 2005 General Election found that just 16.5% of adults with intellectual disabilities turned out to vote (Keeley et al., 2008), just over a quarter of the general turnout rate of 61.4% (UK Political Info, 2016). Unequal levels of voter registration and participation for adults with intellectual disabilities is a significant problem in that it reinforces inequalities, leading to their interests being unrepresented within the UK Parliament, their voices unheard and rights at risk of being ignored.

Keeley et al. (2008) argue that low rates of participation by adults with intellectual disabilities in democratic processes in the UK is not about their capacity to vote, rather it is contingent on whether the person themselves, and their supporters, recognise their statutory responsibility to uphold people's rights to register and subsequently take positive steps to enable access to voting. The literature indicates that it is possible to increase numbers of adults with intellectual disabilities participating in the political process through positively tackling barriers to engagement (Holland, 2016). During the 2015 UK General Election a number of national organisations took this approach, running national campaigns that aimed to support individuals with intellectual disabilities and their carers to exercise the right to participate.

For example, Mencap ran the *Hear my Voice* campaign, which aimed to mobilise adults with intellectual disabilities to make contact with their local candidates and vote. Mencap reported that the campaign resulted in 'hundreds' of people sharing 'selfies' from polling stations as they cast their vote in the General Election (Mencap 2016). United Response ran the *Every Vote Counts* campaign through their 341 services across the UK. United Response's own evaluation reports that 77% of people supported by their services found their Easy Read Guide 'helpful', and that 43% of people voted (United Response, 2015). The Parliamentary Outreach Service also took steps to try and improve the numbers of people with an intellectual disability who had the opportunity and understanding to exercise their vote. Dimensions, a provider of services for people with a learning disability and/or autism, were commissioned to carry out this work, which was called *Love Your Vote* (Dimensions, 2015). An evaluation has not yet been published of the impact of this campaign, which provided people with resources to contact their local MP, register to vote, and cast their vote.

Holland (2016) observes that transactional approaches towards removing barriers to participation, such as taking action to address the accessibility of

polling stations, producing easy-to-read documents and assuring assistance is available, may not on their own be sufficient to increase participation on the part of adults with intellectual disabilities in UK elections. Kjellberg & Hemmingsson's (2013) qualitative study of voting patterns of adults with intellectual disabilities in Sweden suggests that a social policy and social environmental context (Hatton 2004) are significant influencing factors on people's sense of citizenship, their belief that they have a right to vote and do not require a mental capacity test to do so, and ultimately the resultant behaviours on polling day.

During the 2015 General Election, social workers in some local areas mobilised to take positive social action to redress the continued prejudice which adults with intellectual disabilities experience (Redley et al., 2012), running campaigns that they called *Promote the Vote*. It can be argued that the critical evolution of the social model of disability, which reframed outcomes for people with a disability as a response to society's failure to provide appropriate services and meet needs (Oliver, 1983), towards a model of universal citizenship promoting dignity and equality as fundamental to overcoming dehumanisation and exclusion (Kayess & French, 2008) is coherent with the focus on social justice within social worker training (Morgan, 2012).

One of the local *Promote the Vote* campaigns run by social workers was selected for a service evaluation as defined within National Research Ethics guidelines (ESRC 2015). Drawing on previous empirical studies, the evaluation was designed to answer the research question:

To what extent were adults with intellectual disabilities living in community support settings enabled to participate in the 2015 UK General Election?

The evaluation included managers of residential units and supported living services for adults with a learning disability, analysing their understanding of the MCA (2005) and the extent to which they were upholding positive obligations to ensure that people experienced their right to have their capacity to participate in elections assumed. The participants in the evaluation were 92 adults who had the label of intellectual disability, aged 18-64 and who were living in 15 shared community-living settings. Six of the settings were registered with the Care Quality Commission as supported living settings, and nine were registered as residential care homes. Nine managers of the settings

also participated in the evaluation. All participants' contributions have been anonymised.

Methods

Design

The study design applied the definition of social work research methodology proposed by the British Association of Social Workers (British Association of Social Workers, 2012), which is that social work practice is based upon 'a systematic body of evidence informed knowledge derived from research and practice evaluation' (p. 7). In keeping with Joint University Council Social Work Education Committee research ethics (JUC, 2016), consideration was given to ethical and moral issues at all stages of the study design, and investigation and specific consideration was given to participant recruitment and consent. Service provider managers were invited to participate in semi-structured interviews, but were also informed that they did not have to take part if they chose not to do so. A participant guide for adults with an intellectual disability, *Have Your Say – Why Voting Is Important*, was produced in easy-read format and was distributed to people with intellectual disabilities who were living in the 15 settings included in the study. People who lived in the settings included in the study were advised that they did not have to participate.

Quantitative data that had been previously collected by the service were collated in relation to voter registration and turnout on polling day. The decision to gather quantitative registration and turnout data and qualitative interview data for the evaluation was a pragmatic one. The research strategy was of a small-scale review that meets the definition of a service evaluation under National Research Ethics guidelines (ESRC, 2015). 'Real world' practitioner-led service evaluations often involve a blending of both inductive and deductive processes of generating, testing and confirming or otherwise theories (Gray, 2009; Creswell & Clark, 2011).

In addition, semi-structured telephone interviews were conducted with the managers of residential and supported-living services for each setting the week prior to the closing date for postal voter registration. The interviews were structured around five questions developed with reference to previous research. The questions covered:

- Whether many of the people living in the settings had expressed an interest in voting, and how many had done so.

- Whether people living in the settings were registered to vote.
- Whether participating in voting during the May 2015 General Election was included in support plans.
- Whether they were aware there was no mental capacity test for voting.
- Whether they thought voting was a worthwhile activity for adults with an intellectual disability?

The output from the interviews were written up immediately and recorded on a template, which followed the structure of the five questions, but also provided space for recording of unstructured field notes (Grey, 2004). Unstructured data was collected in recognition that the process being followed was transactional. However, the exploration of issues within social work practice is relational and may not follow a pre-structured path.

Procedure

Quantitative data on participation rates and voter turnout were analysed using descriptive statistics of frequencies and tested for significance using Fishers Exact Test, as appropriate for 2x2 tables. Qualitative data were managed using NVivo 10 software. Interviews with service provider managers were transcribed, and a word frequency analysis was performed on the transcripts to explore the data using visualisation tools and identify themes acting as barriers to participation. During the course of the analysis the interview scripts were revisited several times by the social work managers conducting the evaluation to look for deeper insights and inference from the responses recorded.

Materials

Quantitative data held within by the Local Authority Democratic Services Team were used to analyse voter registration rates and turnout on polling day. The Local Authority Democratic Services Team logged by person and address registrations for postal voting and votes cast on the day by address and person casting the vote. Ten per cent of adults with intellectual disabilities included within the evaluation registered for postal voting. In 2015 the data for postal votes cast was not recorded in the Local Authority where this evaluation took place, so there was no available data on the outcome from postal registration. It is not possible to include whether or not they cast their vote in the final analysis.

Analysis

The evaluation team followed a process of iterative review of contextual factors, personal perspectives and interpretation of data collected during the evaluation. The findings from the analysis should not be unduly generalised or used to extrapolate wider implications for other populations. They only provide access to insights and understanding of the phenomena studied within the specific context of the sample cohort. By nature, issues of particular relevance to those participating are amplified within a small sample. Overall, this evaluation should be viewed as a contribution to an emerging knowledge base on the barriers that prevent and motivating factors that enable participation of adults with intellectual disabilities within the democratic process and the extent to which rights under CRPD Article 29, the right to participation in political and public life, are being upheld in practice.

Findings

The quantitative findings relate to participation in the 2015 UK general election of 92 adults with intellectual disabilities, who were aged 18–64 and were living in 15 shared living community settings at the time of the election (see Table 1). The findings were that people with an intellectual disability were less likely to register or participate in the election when compared with the general population. Analysis of voter registration found that 23.9% of people in the sample had registered to vote. This compared with 87.4% of the general population who were registered on the UK Electoral Register in 2010 (Political and Constitutional Reform Committee 2014). On the day of the election, fewer than one in 10 people with an intellectual disability (8.7%) turned out to vote, compared with 65.1% of the general population who participated in the 2010 and 66.1% in the 2015 General Election (UK Political Info 2016).

Table 1: Registration and Turnout in the General Election 2015

	<i>N</i>	%
Registration status (<i>n</i> = 92)		
Registered to vote	22	24
Unregistered	73	76
Type of vote (<i>n</i> = 22)		
By post	8	36
In person	14	64
Turnout on 7 May (<i>n</i> = 14)	8	57

Two types of shared living setting were included in the study: residential care homes registered with the Care Quality Commission (CQC), and supported

living settings. Participation rates from people living in the different types of settings were compared to examine potential differences in participation by setting type. There was no statistically significant difference found in registration rates ($p=0.46$ Fisher's Exact Test) or turnout rates ($p=1.00$ Fisher's Exact Test) between the two different types of setting (see Table 2).

Table 2: Registration and Turnout by Type of Setting

	N	%
<i>(n = 15)</i>		
Supported Living	6	40
Residential Care Home	9	60
<i>Registration Status Care Home (n = 51)</i>		
Registered to vote	14	27
By Post	5	9.8
In Person	9	17.6
Unregistered	37	73
Turnout on 7 th May (<i>n = 9</i>)	4	44.5
<i>Registration Status Supported Living (n = 41)</i>		
Registered to vote	8	19.5
By Post	3	7.3
In Person	5	12.2
Unregistered	33	80.5
Turnout on 7 th May (<i>n = 5</i>)	4	80

The qualitative findings indicated that there were complex and multi-layered aspects that were influencing democratic participation on the part of adults with intellectual disabilities. During analysis, two conceptual categories emerged against which the data were explored:

- Cultural and relational aspects including provider staff values and power relations between people living in the settings and staff members; and
- Structural aspects such as including positive action to take reasonable adjustments and enable voter registration.

Understanding on the part of providers' service managers of the statutory principle that mental capacity is assumed (MCA 2005) was identified as a

secondary theme during the analysis, an outcome which was potentially predictable given previous research findings (Keeley et al., 2008; Kjellberg et al., 2013).

Mental capacity was framed as justification for the behaviours of people working in settings to prevent adults with intellectual disabilities exercising their rights. The following extracts from field notes illustrate views of the services managers participating in the study in responses to a question about their understanding of intentions on the part of adults with intellectual disabilities to participate in the 2015 General Election.

PM1: *“Oh no love, they can’t vote, they have a brain injury”*

PM2: *“Those with capacity will be taken to vote on the day”*

PM3: *“They have no communication skills so couldn’t tell you their decision, they couldn’t hold a pen to make the cross”*

PM4: *“They’re not able to understand, they’re mentally handicapped”*

PM5: *“They’re badly brain damaged; they wouldn’t be able to vote”*

PM6: *“6 of them lack capacity. The 2 who have capacity might want to vote, if they want to they might register”*

On second reading, the idea that people needed to be prevented from voting as they might make ‘unwise’ decisions was identified within the interview transcripts. For example:

PM7: *“They can’t vote. They would vote for who they liked the look of”*

Power and controlling influences being exerted over people by staff within settings was also identified as a theme:

PM8: *“If anyone took them to vote it wouldn’t be their vote that would be recorded”*

A further finding was of asymmetric power dynamics within the settings. Staff were found to be acting as ‘gatekeepers’ to democratic participation on the part of adults with an intellectual disability who they were employed to support. Examples of this power dynamic in action are found in the following reactions to the request from the team conducting the study for social workers to visit and distribute copies of Easy Read Guides to people living in the settings or provide support to assist people to attend polling stations on the date of the election.

PM9: *“I have no objection to you following up the call with a visit to deliver the guides”*

PM10: *“I have no objection to the guides being delivered”*

PM11: *“No assistance is needed to get people to the polling station”*

These responses indicate that people managing settings where people who have an intellectual disability live, believe that they have the right to determine whether or not to allow access to information about the election or receive assistance to enable participation.

There were no instances observed during the analysis of the decision in relation to a follow-up visit taking place, during which Easy Read Guides would be delivered, being devolved to the adults with intellectual disabilities who the guides were intended for. Rather, the pattern observed was one of interference and control on the part of provider managers (van Dijk, 2001), who positively framed themselves and their actions as protectionist towards adults whose humanity and access to human rights in the form of the right to vote was different to their own.

Discussion

The findings were of very low registration (23.9%) and participation (8.7%) rates amongst the sample of adults with intellectual disabilities during the 2015 UK General Election. Two thirds of service provider managers who participated reported not understanding that there is no mental capacity test to determine if UK citizens are allowed to participate in elections. The qualitative findings indicated that there were complex and multi-layered aspects, which were influencing democratic participation on the part of adults with intellectual disabilities. Mental capacity was framed as justification for the behaviours of people working in settings to prevent adults with intellectual disabilities exercising their rights.

Article 29 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) requires signatories to guarantee the same political rights and opportunities as non-disabled citizens. There is no mental capacity test in relation to the right to vote. However, questioning of the mental capacity of the adults with intellectual disabilities to be able to participate was a theme identified during analysis of the interviews with the service managers who participated. On initial review, the narrative framing of the right to vote was in terms of mental capacity determining legal rights.

Hood's (2016) evaluation of the participation of adults with intellectual disabilities in the 2014 Scottish Independence Referendum found that staff attitudes and approaches were significant barriers to participation. Hood observed that staff had a powerful role and that they were able to 'exert' strong influences over the people with intellectual disabilities they were providing support for. The implication was that adults with an intellectual disability lacked the mental capacity to prevent themselves from being unduly manipulated into choosing to vote for who they liked the look of the most, compromising the whole process of electing legitimate representatives (Agran & Hughes, 2013).

Baker J observed in *CC v KK* (2012) the danger of what he described as being the 'protection imperative' resulting in professional workers treating the person as unable to make a decision just because they perceive that decision to be '*unwise*'. However, the right to make unwise decisions is enshrined in statute in Principle 3, Section 1 of the Mental Capacity Act (MCA) (2005). As observed by Mostyn J in *A NHS Trust v P & Anor* (2013), the purpose of the MCA is not to wrap the person in 'forensic cotton wool' but to enable individuals to make the 'same mistakes' as any other human being. This includes exercising the right to vote for whomever the person may choose as their duly elected representative, without having their capacity to make a 'wise' decision about who to vote for being questioned.

The frequency with which instances of mental capacity were raised as a barrier to participation indicates that more research to examine the extent to which understanding of mental capacity law affects and influences democratic participation of adults with intellectual disabilities would be of benefit to policy makers and practitioners within the social care field.

Conclusion

The findings from this evaluation were that adults with intellectual disabilities living in community support settings experienced discrimination which resulted in disenfranchisement during the 2015 UK General Election. Whilst in the UK there is no mental capacity test determining the right to vote, the service managers who participated in the study framed their justifications of low rates of voter registration and participation of adults with intellectual disabilities living in the settings they managed in terms of people lacking mental capacity. There are two key practice implications arising from these findings indicating where social work managers and commissioners could improve participation rates in future elections through building on the emerging meta-narrative on the

impact of the MCA (2005). The findings indicate the need for more work to increase confidence and understanding on the part of adults with intellectual disabilities of their rights as citizens to register to participate in democratic processes upheld. The findings also indicate that there is a need to invest in the knowledge and understanding on the part of staff working within services designed to support people with an intellectual disability to live an independent life about their rights. These include the right to democratic participation under Article 29 of the UN CRPD and the lack of a mental capacity test to determine if as a UK citizen they are allowed to participate in elections. The study also indicates that further research and training into the wider application of the statutory principles of the MCA (2005) would be of benefit to practitioners and policy maker within the social care field.

Acknowledgements

The authors wish to note thanks to Paul Thorpe, for his contribution to the delivery of the project; Mark Harvey, Principal Social Worker in Hertfordshire, who acted as critical friend and key advisor to this project; and Professor Chris Hatton, Lancaster University, for his kind comments on early drafts.

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