Service users' experiences and views of support for decision making

Webb, P., Davidson, G., Edge, R., Falls, D., Keenan, F., Kelly, B., McLaughlin, A., Montgomery, L., Mulvenna, C., Norris, B., Owens, A., & Irvine, R. (2020). Service users' experiences and views of support for decision making. *Health and Social Care in the Community*, *28*, 1282-1291. https://doi.org/10.1111/hsc.12961

Document Version:
Peer reviewed version

Queen's University Belfast - Research Portal:
Link to publication record in Queen's University Belfast Research Portal

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Conflict of Interest: Gavin Davidson is the Praxis Chair of Social Care at Queen's University Belfast and this post is part funded by Praxis Care.

Abstract

This article presents the findings from a qualitative, participatory research project which explored how people with intellectual disabilities and/or mental health problems have, or have not been, supported to make their own decisions. The aim of the research is to help inform how supported decision making, as required by Article 12 of the UN Convention on the Rights of Persons with Disabilities, can be effectively operationalised. The project provides an overview of experiences of support as well as identifying which supports are valued. It was conducted between July 2017 and July 2018 and was a partnership between disabled people, service providers and a University. It involved peer researchers interviewing 41 people with mental health problems and/or intellectual disabilities, in community settings, about their experiences and views of support. The key findings include that decision making is a central aspect of people's lives. Participants discussed the positive role which decision making can have but also how it felt when they were not supported to make their own decisions. Participants said there were three main things that make decision making harder: the type of decision; the role of other people; and what the outcome might be. Time was consistently identified as a very important factor. In terms of support, people said they would like: practical support including more accessible information; emotional support including someone to talk to; and sometimes the options to choose from. There was very little mention of existing, more formal processes of support such as advance decisions or care planning. The peer researcher aspect of the project was valued by participants. The main implications of the research are for how support for decision making should be provided including the need for an individualised approach as the support needed varies across decisions, time and people.

What is known about this topic:

• Making decisions is central to human rights, freedom and independence

• Article 12 of the UN Convention of the Rights of Persons with Disabilities requires that people with disabilities should have equal recognition before the law

• This involves providing support for people, whose decision making may be impaired, to make their own decisions

What this paper adds:

• Support needs to be individualised and responsive. The importance of time was a major theme.

• Further research is needed to explore the effectiveness of approaches including when support may become coercion.

• The peer research aspect of the study was valued by participants, the peer researchers and the rest of the research team.

Introduction

Making decisions about your own life, including decisions about your health and social care, is a key aspect of independence, freedom and human rights. Mental health law has previously allowed compulsory intervention even when a person has the decision making ability to refuse intervention. This discriminates against those with mental health problems and intellectual disabilities. In May 2016 the Mental Capacity Act (Northern Ireland) became statute law and was partially implemented on 2nd December 2019. In contrast to other countries this law will eventually replace,

rather than be in parallel to, mental health law. This will address the discrimination of separate mental health law and is a positive response to the 'equal recognition before the law' requirement of Article 12 of the UN Convention on the Rights of Persons with Disabilities which promotes a supported decision making approach for all. A core principle of the new Act is that people are "not to be treated as unable to make a decision... unless all practicable help and support to enable the person to make a decision about the matter have been given without success" (Article 1(4)).

Supported decision making has been defined as an "approach to decision making that involves providing a person with impaired capacity the support they need to make their own decision" (Victorian Law Reform Commission, 2011, p. 19). The recognition of decision making as a critical component of personhood and citizenship is also important for the realization of equal rights (Bach & Kerzner, 2010; Flynn & Arnstein-Kerslake, 2014). As such, Professor Amita Dhandra suggested that "supported decision making would be better conceived as a universal component of community life for all citizens, rather than something targeting only those with a disability" (Carney, 2017, p. 49). It is sometimes distinguished from shared decision making which has a relatively narrow focus on health care professionals working with service users to make health care decisions although supported decision making does also refer to health care decision making (Simmons and Gooding, 2017).

Carney and Beaupert (2013) argue that implementing supported decision making is complicated as it is 'conceptually ill-defined', leaving it open to multiple interpretations. Carney (2017) goes further to suggest that the introduction of supported decision making 'has largely been a case of much talk and little real

action' (p. 18). Shogren and Wehmeyer (2015) have developed a helpful theoretical framework for research and intervention design but, in practice, this work is still developing. Other potential barriers to providing effective support include slow progress on legislation reform, the cost of implementation, the need for staff training, inconsistent practices, concerns regarding safeguarding, and a lack of involvement of people that require decision-making support in developing services (Goldsmith, Skirton & Webb, 2008; Hoole & Morgan, 2011; Carney, 2017). In addition to the institutional barriers to supported decision making, people with intellectual disabilities have also identified the following challenges: (1) adults with intellectual disabilities are often viewed as children; (2) a power imbalance exists between the supporter and supported; (3) confusion over differences between 'mental disorder' and 'intellectual disability' by supporters; (4) the need to balance protection against autonomy (and risk taking); (5) a failure to consider that different decisions may require different levels of support; and (6) the absence of a trusting relationship between the person being supported and their supporter (Jamieson, Theodore, & Raczka 2015; People First (Scotland), 2017).

A number of empirical studies have documented the experiences of individuals and supporters in the supported decision making process. One of the key findings has been that 'decision-making is a dynamic and interactional process' (Knox, Douglas & Bigby, 2015, p. 15) and that the subjective relationships between the individual, supporter and the context is at the heart of the process (Knox, Douglas & Bigby, 2015; Jamieson, Theodore, & Raczka, 2016; Knight et al., 2018). Other studies have also discussed the relationship between the individual and the supporter, particularly focusing on the individual's feeling of powerlessness if there was not a good working

relationship between them (McDaid & Delaney, 2011; Jamieson, Theodore, & Raczka, 2016; People First (Scotland), 2017). Harding and Tascioglu's (2018) qualitative study with people with intellectual disabilities in England reported a range of positive practice, especially for everyday decision making, although more difficult decisions were reported to be less well supported.

Overall in the literature (Hoole & Morgan, 2011; Douglas, Bigby, Knox & Browning, 2015; Knox, Douglas, & Bigby, 2015; Stavert, 2016), effective supported decision-making processes tended to: 1. include a commitment to the individual (including knowing the person well and respecting wishes for discretion or the involvement of additional parties); 2. follow support principles (including communicating in an open and non-challenging way, being honest, absence of undue influence or conflict of interest, and providing clear information in different formats); 3. be clear about the roles of everyone involved; 4. adhere to relevant legislation; and 5. provide a range of flexible/adaptable strategies. The importance of culturally sensitive support and the need for maintaining records of the support have also been highlighted (Piffaretti, 2012; Kileen, 2016).

Many benefits of supported decision making have been identified, including increased personal autonomy and control, a clearer structure within families and professional relationships in making decisions and plans, and ensuring legal capacity to make decisions is respected (Chartres & Brayley, 2010). Research in mental health services has also found that when people feel they are listened to, even if they disagree with the outcome, they are less likely to feel dissatisfied with the service provided (McKenna, Simpson & Coverdale, 2000; Galon & Wineman, 2010).

It can therefore be concluded that supported decision making can have wider societal benefits through ensuring participation and recognition of citizenship rights, developing a more inclusive approach to the realization of disability rights, and developing a framework in which individuals are empowered to gain more control over their lives (Stavert, 2016).

There is a consensus in the literature about the need for more research on supported decision making and, in particular, robust and rigorous trials (Douglas, Bigby, Knox & Browning, 2015; Carney & Beaupert, 2015; Carney, 2017). There is still a great deal to learn about the practicality of different approaches to supported decision making and the experiences of the supported, supporters, and those implementing these approaches. A further aspect of the rationale for this project is the possibility that positive intentioned approaches to supported decision making could still be operationalised in ineffective or even negative and coercive ways (Stone et al., 2019)

This research project was therefore designed to explore how people with mental health and/or intellectual disabilities have, or have not been, supported to make their own decisions. It also asked participants what works for them and sought their ideas on how people with mental health and/or intellectual disabilities should be supported to make decisions. The relevant theoretical framework for the research therefore highlighted the importance of understanding people's experiences of decision making from their own subjective, socially constructed perspectives. Consistent with this theoretical framework was therefore a participatory approach to the design, analysis and reporting of this project (Schubotz, 2019). The overall aim of the

research was to inform how the new support principle should be implemented in practice.

Methods

The study was designed to explore experiences of decision making using qualitative interviews with people with mental health problems and/or intellectual disabilities. The scope was broad and included experiences of decision making processes across all aspects of life including health, welfare and finances. It also explored decision making at all levels including everyday routine decision making (such as what to wear, eat, do that day) to major life decisions (such as where to live, who to go out with, health care decisions with long-term consequences). People with mental health problems and/or intellectual disabilities were the focus as the literature suggested that these groups have been subjected to relatively high levels of substitute decision making and it also enabled some comparison between a range of experiences. Four peer researchers, two with intellectual disabilities and two with mental health problems, were employed to design data collection tools, interview participants in the study, conduct data analysis and disseminate the findings. The peer researchers were recruited through open recruitment managed by two of the research partner organisations who were also service providers - Praxis Care and Mencap NI. Successful applicants had a range of previous experience of research from post-graduate study to this being their first project. All completed a two day training course delivered by members of the research team. The training included: a project overview, introductory research methods, role-plays, ethics, self-care, analysis and report writing. The co-production approach to this project was informed by the social constructionist perspective that suggests to better understand people's

experiences their subjective perspectives on the issues is central. One way of helping inform the design of the project was therefore to work with peer researchers who bring expertise from their own experiences. There had been some service user involvement in identifying the need for this research but it should be acknowledged that the broad focus of the research was set before funding was secured and the peer researchers were employed. After that they were involved in all aspects of the research project with appropriate, individualised support to facilitate their work and to address some, at least, of the power imbalances involved.

Procedure

Ethics/consent and recruitment procedures

Ethical approval was provided by REDACTED. Research participants were recruited through Praxis Care and Mencap NI.

Potential participants were purposively selected to attain a range of experiences of supported decision making and to ensure a broad demographic range (i.e. gender, age, urban/rural). Potential participants were initially invited to take part in the study via phone call, by email, by talking directly with a staff member who was familiar with the study or by reading a letter and explanatory leaflet. All potential participants were provided with information about the study (including in Easy Read formats) and provided written consent before proceeding. Information about those who were approached but declined to be involved was not collected.

Participants were invited to take part in an interview with one of the peer researchers (who was accompanied by a member of the wider research team who provided transport and support if needed) at a date, time and place which was convenient for them. All interviews were held in participant's homes/or in Praxis Care or Mencap NI facilities (including offices and independent living units) across Northern Ireland.

Semi-structured, in-depth qualitative interviews were used to explore people's experiences, the approaches to support used and what worked for them. Forty-one people with mental health problems and/or intellectual disabilities were interviewed between November 2017 and January 2018. Participants ranged in age from 22 to 80 years old with an average age of 48 years. The majority of the sample were male (n=29, 71 per cent). As this was an exploratory, qualitative study it is not intended to be representative of all people with mental health problems and/or intellectual disabilities and as participants were recruited through service providers they may have relatively high levels of need for ongoing support. Participants were interviewed by two members of the research team. Generally the peer researcher led the interview with support from a member of the wider research team.

Interviews

The interview was guided by a semi-structured interview schedule developed by the research team, international advisory group and following a review of the international literature (see Appendix One). The schedule was structured around three key areas: experiences of making decisions, approaches to support and ideas for future support. Prompt sheets were also developed to support the interview

process, acting as visual aids to present questions and possible responses in a clear and concise format. Interview duration ranged from 15 to 70 minutes.

Data analysis

Unique participant ID codes were allocated to audio recordings prior to transcription. Participants were not given the opportunity to select a pseudonym although this may have been a more person-centred approach. Interviews were transcribed verbatim and transcripts were anonymised. An initial coding frame was developed by the whole research team by selecting a sample of transcriptions, independently identifying codes and then discussing them in workshop process. The data were then also analysed independently and in more detail by one of the peer researchers and another member of the research team using a thematic analysis approach facilitated by QSR NVivo (Version 11.0). The final themes were agreed through discussion with the whole team.

In order to further promote the reliability and validity of the research findings the results of the data analysis were presented to all those who were interviewed at a participant workshop to ask for their feedback and comments on the emerging themes and the possible recommendations that could arise from them. This included that some participants were willing to be further involved in helping to inform how supported decision making could be developed and this was included in the further dissemination of the findings. A summary of the research findings was sent to all participants who were unable to attend the event.

Findings

The thematic analysis identified two main areas: experiences of decision making and of support. Participants are identified according to whether their reason for accessing services related to their mental health problems (MH) or intellectual disabilities (ID)

Experiences of decision making

Types of decisions

Types of decisions included everyday decisions (i.e. routine tasks e.g. shopping; health care e.g. exercise and diet; and financial decisions e.g. purchases); important recent decisions (e.g. education and employment; health, housing and socialising) and major life decisions (e.g. living arrangements, serious operations):

> "Moving into my own house – so that was a big decision for me….I've always lived with my sister after my parents died, so that was a big decision to move out on my own…." (ID006)

Having choices

Participants generally reported they had a variety of choices in life and family members were often those who provided options. For some, the perception of having choices changed over time – perhaps due to changes in attitudes of others:

> "I've come to the point now and I've come to the doctors that I trust, the doctors now are more forward and more understanding, they will listen to you now, they will listen, if you feel the medication is not working you have a right to say that to the doctor now, years ago you hadn't that right, you had no say in the matter" (MH10)

Others indicated their choices were limited resulting in them feeling unhappy, uneasy, and under pressure. Interestingly, a minority of participants discussed their preference for fewer options. However, the majority of participants preferred a number of options to give "more of a variety" (MH008).

Feelings

Feelings when making decisions varied and were often dependent on the type of decisions to be made and having support.

> "Money wise I am not confident about, like if I had invoices or bills that I had to pay I think I would need assistance from my father to be able to sort that out, but in terms of shopping and getting food for myself and like say this time of year getting stuff for Christmas I am actually happy enough to do that myself." (ID018)

A range of positive feelings relating to decision making were reported including feeling happy, comfortable, fortunate, independent, confident, proud, excited, rewarded and untroubled at the prospect of having to make a decision:

> "I feel very confident that like if I have made my own decision and people accept it and then I would have felt I would have achieved something that hadn't really been achieved before, and that I wouldn't have not needed anybody else to go through while making that decision" (ID018)

Others reported negative feelings: "I don't like myself making decisions" (MH019) with emotions ranging from indecisiveness, procrastination, sadness, fear and anxiety. Negative feelings around decision making appeared to be alleviated via support from others and having all the necessary information:

> "I might get anxious and everything else, and that is when the staff support will come in to sort of take some of the stress off me" (MH001)

Factors that make decision making difficult

Feelings when making decisions were often interlinked with factors which can make decision making more difficult such as the type of decision to be made, the impact on others, the extent to which others influence/make the decision (e.g. pressure from others) and the outcome of the decision: "If it turns out to be a good thing then I feel good about it" (MH015).

Time pressure was a particular challenge when making decisions, for example, moving to a new home at short notice and being put under pressure by others to make decisions. Having more time to make decisions was highlighted as important, in particular time to access information/support and to think about it. Some indicated they adopt a cautious approach to decision making and do not let others put them under pressure – "most things I just tackle on my own time." (MH004). The person's current *state of health* was also relevant, particularly for those with mental health problems whereby mood, deterioration in mental health, use of substances and the effects of prescribed medication were often cited as impairing decision making with participants highlighting how the need for support may vary.

Others making decisions and perceptions of capacity

Those who made decisions on behalf of participants included family and professionals. Feelings when others made decisions included confusion, unhappiness, uneasiness, anger, stress and anxiety with one participant reporting "I should have been asked" (ID015). Examples included decisions over living arrangements, education and finances, and medication was a frequently cited example (particularly among the mental health participants). There was frustration around the lack of input into decisions about the prescribing of medication (i.e. dosage) and requests to reduce/stop medications being ignored. Decisions around changes to medication without consultation caused anxiety for a number of participants.

Some said that they did not feel able to make some decisions.

> "I know I'm not right, I'm not fit to work and I'm not fit to socialise and I'm not fit to make some decisions for myself." (MH011)

Decision making history and hindsight decision making

Some participants reported having had long-term difficulties with decision making and attempted to identify the roots of such difficulty e.g. difficult relationship with parents; lack of autonomy. Changes in decision making over time were identified i.e. the ability to make decisions as they got older; changes in priorities (e.g. no longer abusing substances; becoming capable of managing medication) and more opportunities/support - "those options weren't there for people with a learning disability, the way they are now" (ID013). Some reported regret about past decisions; others reflected on not having enough information at the time.

> "I have actually made some quite bad choices in regard to decision making and I have been trying to forget about some of those decisions and actually I have tried to get on with my life and every day and continue on every day without having to reflect on those kind of decisions that had sort of affected me." (ID018)

Experiences of support

Sources of support

Support was provided primarily by family members but also by friends, housemates, work colleagues, health and social care professionals and organisations, educators and other sources (e.g. drama groups). Participants recommended these sources of support and a wide support system.

> "The support that I got from my mummy and my daddy has been crucial to me and I wouldn't want it any other way, and the support that I have with colleagues and friends throughout my life."(ID013)

In general participants with intellectual disabilities were more positive about the support they had received for making decisions, especially from family. Participants also provided accounts of providing support to others. In general, participants

actively sought support when necessary e.g. approaching staff for advice. Some had concerns about not being assertive enough in asking for help "Sometimes I'm afraid to ask for help in case they're busy, or I want to save time, or I don't want to cause a fuss."(ID017). Where support was unavailable, participants relied on sources such as the internet. The importance of support for family members was also highlighted:

> "When I'd been sick and my Mum used to ring for help for them – they said, this is your problem, you deal with it." (MH001).

Support required during periods of transitions and the impact this had on decision making was also highlighted. Examples included major operations, release from prison and leaving supported living or psychiatric care.

Qualities of a good supporter

The qualities of a 'good supporter' were identified as someone who was: approachable, accessible, available and consistent; had a good relationship with the service user; similar interests; someone they could talk to; a good listener; acknowledged the service users perspective; empathic; understanding; kind/caring; helpful; good social skills; provided clear advice; was experienced/qualified and knowledgeable; and knows the need of the service user; trustworthy, respectful and showed genuine interest in the service users life.

> "Good support would be like, to be there for the person and for the person to know that you can phone them up or go and see that person whenever you need to see them. And if that person is not there, maybe to have somebody else there..." (ID006)

Types of helpful support

Helpful support recommended for the future included: consulting with the service user; inviting them to attend meetings to inform policy/practice; being on staff

recruitment panels; attending review/progress meetings; providing information in an accessible and clear format, tailored to their needs; listening to their views, treating them with respect; more staff and more time with staff.

> "Talking it over with them, actually talking over in a review like with their service manager or the assistant manager and the social worker and whoever, I get a choice whoever I want at that review" (ID017)

Current helpful sources of support consisted of practical, informational and emotional support. Practical support included management of medication; prompts or reminders for appointments; financial support (e.g. banking); assistance with routine tasks; documenting progress in diaries; seeking advice; securing employment and support in the workplace; showing service users what to expect (e.g. new accommodation, transport); securing housing near family members; education and learning support; technology; development of skills and knowledge; and social activities.

Informational support included advice on budgeting money; reading and explaining e.g. explaining letters/forms to service users; advice on physical/mental health (e.g. what to do when feeling down); and tailoring information to meet individual needs. "That helps yeah, she can read it out for me or she can explain to me what's going on, it's easier to take it verbal." (MH014)

Emotional support included peer support; encouraging service users to be independent; providing reassurance on decisions; and having a wide support network.

> "Being able to talk to them about your feelings and your anxieties, and knowing that there is a good structure there, I like the sense of community around here and the few friends that I talk to." (MH011)

Participants discussed whether people should always be supported to make decisions. Reasons for supporting decision making included – the importance of free will/independence; being their 'own person' (ID016) and being able to 'make up their own things in their own mind' (MH013). Benefits included assisting people in feel good and coping. Participants highlighted the importance of being included in what's decided for them (and understanding the pros and cons); the importance of helping them to make the right decision (when given advice/support); and discussed how support can make decision making easier. The importance of safeguarding people with intellectual disabilities was highlighted and other issues were identified such as the specific needs of the individual (and using the appropriate accessible information) and the type of decision.

> "I think it's important for people with a learning disability to have their own choices in life but be supported and be given the option, but obviously they do be to keep them safe too." (ID013)

Circumstances where others may have to make decisions (or partial decisions) were identified including when the person lacked capacity (e.g. mental health crises; emergency operations); and not having support (e.g. no family members). Examples of those who could make the decision included family members and carers (while respecting the individual's wishes). In general, participants reported individuals should be supported at all times, where possible.

> "When you're mentally unwell, definitely they should take – not all of your say, but about 80% of your say off you, just until you get better, and then ... gradually build you back up again to where you were initially before you got ill." (MH001)

Others gave examples of poor decision making as opposed to not being able to make decisions e.g. listening to friends rather than parents or staff.

In summary there were a number of key themes from the findings: the need for a wide circle of support and recognition of inter-dependence; supported decision making as a dynamic process; the need for a culture of listening; the impact of values, attitudes to impairment and paternalistic practice; the importance of trusted relationships built up over time; accessibility issues: accessible information, processes and additional time to make decisions; importance of supporting people to build their assertiveness and confidence to make decisions (and linked to this – the helpfulness of peer support and emotional support).

Discussion

The findings provide insights into disabled people's experiences of the range of approaches provided to support decision making; what approaches work for whom; and what people's preferences are for support. The participants in this study identified a wide range of experiences of decision making. Many participants identified having a variety of choices in their life and it was noted by some that the opportunities to make choices had improved over the years. Generally, the opportunity to make decisions was considered to be a positive experience which resonates with the findings from Harding and Tascioglu's (2018) study.

Participants identified three broad factors which could make decision making more difficult. These relate to the type of decision to be made, the impact on, or influence of, others and the outcome of the decision. The importance of relationships was highlighted, reinforcing the work of Knox et al. (2015), and this included concerns around the pressure of trying to please other people. Another significant factor related to the pressure of time. Participants identified that having time to think about

a question, time to think about the answer and being able to access information and support while considering the decision, were important factors in supporting decision making.

Participants' health was also identified as an important factor, particularly in relation to mental health. How participants viewed their decision making capacity was also deemed to be important. Some participants perceived that, either currently, or some time in their past, they did not have the capacity to make decisions and had welcomed the input of others. Perceptions of incapacity may however reflect unhelpful and internalised negative attitudes to disability. In discussing experiences of decision making, some participants described their personal history, reflecting on potential causes of their difficulty in decision making and identifying behavioural patterns in how they made decisions. Moreover, some participants discussed regrets over decisions they had made in the past. These included issues relating to how money was spent, to their living arrangements, friendships, education, medication, work related decisions and lifestyle choices. It was evident that decision making experiences were often viewed in the context of relationships; many positive aspects related to the support and empowerment received from others, whilst negative experiences often related to attitudes to disability.

Participants identified a wide range of experiences in terms of the support they either needed or received in making decisions. As Knight et al. (2018) had found, people may have different positions on support and these may overlap and change over time. Support included the opportunity to access information, review pros and cons and get feedback from others. The central importance of family members in

providing support in decision making was highlighted along with support from a wide range of others. Although there were some exceptions identified, participants reported actively seeking support when necessary. The qualities of a 'good supporter' related to characteristics of the individual, to the quality of the relationship and to the knowledge and experience held by the supporter. It is interesting to note that many of the qualities of a 'good supporter' related to the perceived value base of the supporter, their genuine desire to help and their ability to take a partnership approach. This appeared to be given more weight than the skill and knowledge of the supporter.

Helpful sources of support included practical, informational and emotional support. The issue of anxiety in decision making was raised throughout the findings, emphasising the importance of helping individuals to develop confidence. Practical support included both tangible interventions and empowering individuals to develop their own skills and knowledge to manage areas such as: medication; attending appointments; money; employment; accommodation; and transport. Informational support included advice on budgeting money, reading, physical and mental health and tailoring information to meet individual needs. Emotional support included peer support; encouraging service users to be independent, providing reassurance on decisions, and having a wide support network.

Some ways in which people should be supported to make decisions in the future were identified. These included: consulting with the service user; inviting them to attend meetings to inform policy or practice change; sitting on recruitment interview panels; and attending meetings about them. Finally, the reasons why people should

be supported to make their own decisions were highlighted – and included: the importance of promoting freewill, autonomy and independence; the positive value of decision making in helping people to cope better, in respecting their choice and in helping them to make the 'right decision'. The importance of safeguarding people with intellectual disabilities at times was highlighted and this may also be relevant for people with mental health problems.

Whilst there was a general sense that individuals should be supported at all times to contribute to decisions which affected their lives, participants did acknowledge that there may be times when people could not be supported sufficiently to make a decision.

Although it's not the focus of this article, the peer researcher aspect of the project was valued by participants and reported as a positive experience by the peer researchers themselves.

There are a number of limitations of this project from both research and co-production perspectives. It was a relatively small sample of participants all of whom were in contact with services and so it is not necessarily representative of other people's experiences of decision making. Although an interview is a positive method to explore people's experiences in depth, the focus was on potentially complex and potential sensitive issues, and so a series of interviews, with each participant, could have enabled additional exploration of the complexities involved. From the co-production perspective, as mentioned, the peer researchers were involved in initial process of identifying the need for this research and applying for funding. It is now

planned to establish a process through which peer researchers can continue to be involved in research projects including the decision making process about what issues to focus on and to contribute to the design process from the very start.

Conclusion

The main implications for law, policy and practice are for how, in general, support for decision making should be provided. The research findings reinforce the need for support for decision making to be individualised. The support needed depends on a wide range of factors including: the relevant information and how that can be communicated; the type of decision needed; who else is involved; what the possible options are; and what the outcome might be. The support needed will therefore vary across decisions, time and people. The importance of having sufficient time, and not feeling under pressure, was repeatedly identified. There was very little mention of existing, more formal processes of support such as decision making aids, advance decisions, crisis care planning and Enduring Power of Attorney and so considerable efforts may be needed to promote public awareness and understanding of these options and any new developments. This study highlights that to effectively implement the support principle of the Mental Capacity Act (Northern Ireland) 2016, a wide range of flexible support will be needed, including considerable efforts to provide accessible information about how to access and use support. The findings of this project will be used to inform training on the implementation of the Act as well as training focused specifically on supported decision making.

Although much of this project focused on the positive potential of support, the limitations and potential complexities of support should also be further considered as

what is intended to be support may, at times, move into undue influence, coercion and/or abuse. Participants highlighted that they bring considerable experience of support and were open to being further involved in discussing these issues and exploring what approaches to support are the most effective.

Appendix One Semi-structured interview schedule (there are also accessible versions of the participant information sheet, consent forms and interview prompts which can be provided by contacting the corresponding author)

Before starting the interview please provide a clear introduction of your name and role – participants may be particularly interested in the role of the peer researcher so please do take some time to explain this and discuss if need be. Please also go through the participant information sheet to ensure the person is aware of what is involved and then ask them to complete the written consent form if they are willing to participate.

Introduction to the questions – we're interested in finding out about how decisions have been made in people's lives. We want to explore how people have been supported to make decisions. We also want to try and find out what has worked well for people and what has not been so helpful. We're also interested in any ideas you might have for how people can be supported to make decisions.

Areas to explore:

Your experiences of making decisions

• Please tell us about your experiences of everyday decision making (routine – including health, welfare, financial). Prompts – provide examples, what information/support did you need, were other people involved

• Please tell us about your experiences of major decision making (where to live, who to go out with, education, employment, serious health, welfare and financial). Prompts – provide examples, what information/support did you need, were other people involved

• How do you feel making decisions?

• Do you usually feel that you have a range of choices? Please ask for examples

• Any examples of decisions you've made which you now might approach differently?

• Are there times when other people have made decisions about your life? Please give examples. How did you feel about that?

• What have been the most important recent decisions in your life? Did you make them?

Approaches to support

• What support has been helpful for making decisions? Prompts – examples of support – information, taking it over with friends/family, advice from professionals

• What makes making decisions more difficult? Prompts – examples of barriers – uncertainty, lack of choice, impact on others

• Please tell us about anything else that might be important in making decisions. Prompts – timing, stress, pressure

Ideas for future support

• Should people be supported to make their own decisions? Why?

• Are there any circumstances in which people can't or shouldn't be supported to make their own decision? For example, in an emergency and/or, if a person, even with support, isn't able to make the decision

• Any ideas about how people should be supported to make decisions? Prompts – who should provide support, what would good support be like, what would a good supporter be like

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