Supporting People with Intellectual Disabilities to make Decisions: An Examination of the Use of the South Australian Supported Decision Making Model

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Submitted in Part Fulfillment of the MA in Advanced Social Care Practice

Date: 7th June 2019

Word Count: 15,856
Signed Declaration

I declare that this dissertation and the research involved in it are entirely the work of the author. This work, or part of it, has not been submitted for a qualification to any other institute or university.

Signature: __________________    Date: ___________________
Acknowledgements

To my family and friends especially my husband Brian, our children Donnacha, Eabha, Arlanna and my mother in law, Eilish. Thank you for all your support and patience you all have given me over the last few months.

To May Quinn, thank you for your support and guidance throughout the years and along with my parents Tom Pat and Margaret, instilling the values of determination and preservation when you really want to do something in life.

To my supervisor Mairead Seery, thank you for your support, guidance and your time which was invaluable.

Finally, to the participants and staff members from the disability service who were involved in supporting this thesis, I would like to thank you for your time and your invaluable contribution.
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Abstract
In Ireland, due to changes in legislation there has been a substantial shift towards supported decision making focusing on the will and preference of people with intellectual disabilities (ID). There is a perception that people with ID are incapable of expressing their will and preference or they lack the ability to make decisions. However, Article 12 in UNCRPD is creating a paradigm shift as everyone is viewed to have capacity unless otherwise indicated. There is little research evidence on working models in Ireland that provide the practical tools to develop decision making capacity in people with ID.
Therefore this research examined a pilot of the South Australian Supported Decision Making (SASDM) model in a west of Ireland disability service. This model focuses on developing the will and preference of people with ID through the discovery of their hopes and dreams. The overall research aim was to gain an understanding of what good support in decision making looks like and how this could be developed further so people with ID can lead self-directed lives. To achieve this the researcher looked at the experiences of SASDM from the perspectives of people with ID (DMs) and staff (FMs) involved in the model. While also exploring the benefits and challenges of using this model in an Irish disability service. As well as distinguishing what skills, training and support people with ID and their supporters (including staff), need to make decisions in order to lead self-directed lives. Eight in-depth semi structured interviews was conducted and thick descriptions of the model was gained.
Overall, this research found positive outcomes for both the DMs and FMs that correlated with past research on SASDM by Wallace (2012) and Westhorp and Ball (2015). For DMs there was an increase in confidence, communication, assertiveness, reduced frustration and higher levels of engagement in the community and so forth. Most importantly there was evidence of an increase in decision making ability and problem solving skills. Furthermore, the study highlighted the untapped potential of DMs and the unheard hopes and dreams. Also, findings highlighted the lack of knowledge all DMs had on their finances and keeping it safe even those who were seen as independent.
For FMs there was an increase in skills, knowledge and changed practices from best interest to will and preference with evidence of creative and innovative practices in order to support DMs to achieve their goals.
SASDM training was influential in building the skills needed in FMs to find out the real will and preference of the DMs in turn building their decision making capacity. Most striking was that the DMs had not discussed their hopes and dreams in planning meetings which was their forum to do so. There was practical challenges highlighted, dependent on the abilities of the person with ID and their reliance on staff and transport. Also the study highlighted the lack of supporters in an unpaid role in DMs lives when no family was present. The implication of these findings show that SASDM had a positive influence in creating a supportive decision making environment for DMs including changing perceptions of supporters on the capabilities of DMs. A limitation of this study due to time constraints was the lack of perspectives from families, supporters and organisational which warrants further research.
Literature Review

Introduction

The introduction of the Assisted Decision Making Act (ADMA) (2015) along with the ratification of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) (2006) represents a substantial shift in the manner in which decision making is informed for people with intellectual disabilities in Ireland. Previously, best interest was the principle that guided decision making and the legislation has replaced this with principles of will and preference. In order for people with intellectual disabilities (ID) to exercise their right to autonomy they first must be allowed to make their own decisions and communicate them with others. For years people with ID were denied their legal capacity to make their own decisions based on their cognitive impairment.

In accordance with legislation, disability providers must adopt supported decision making practices. These practices increased decision making capacity in people with ID while creating changes in the perceptions of professionals, families and the community when interpreting their decision making ability (Werner, 2012). There is little research done on established working models of supported decision making that develop ‘will and preference’ in people with ID in Ireland. However, this research will address this as a west of Ireland disability service is piloting a model created in Australia called the South Australian Supported Decision Making (SASDM). SASDM model represents a proposed new way of working with adults with decision making difficulties to build their capacity to exercise their rights to make decisions and in turn promotes autonomy (Nicholson, 2013). There has been evidence of success with this model in South Australia and this research will examine if it is a viable model in an Irish disability service.

Recent Changes in Irish Legislation

Supported decision making (SDM) derives from article 12 of the UNCRPD which puts a responsibility on the state to provide support for people with disabilities to exercise their legal capacity (Arstein-Kerslake et al, 2017). The UNCRPD are rights that are assured to people with disabilities to increase their access to society, education and employment (UNCRPD, 2006).
SDM provides people with disabilities the chance to access support to exercise their legal right to make their own decisions rather than substitute decision making where someone else makes the decision on their behalf (Office of the Public Advocate (OPA), 2012; Wallace, 2012). The UNCRPD arises from the social model of disability, which recognises that disability results from barriers in the environment and attitudes that affect the full participation of people with disabilities in their own lives and their communities (Gradwohl, 2017). There is evidence to suggest that people with ID are within the most vulnerable group for guardianship/ward of court orders (Killeen, 2016). This has been found to be due to limited alternatives to support for people with ID as a result of isolation by lack of family or friends (OPA, 2012).

In order to comply with the UNCRPD (2006) Ireland developed the ADMA (2015) which places ‘will and preference’ into the heart of decision making for people with ID along with the presumption that everyone has the capacity to make decisions. Under this legislation, capacity is decision and time specific which simply means at the time a decision has to be made, does the person understand the decision, are aware of the consequences and can communicate their wishes using whatever means to support them to do so (Flynn & Arstein-Kerslake, 2014; Flynn, 2018). These decisions need to be supported by ‘enabling conditions’ such as accessible information in the form of communication the person understands, the right support and time to make the decision (Flynn & Arstein-Kerslake, 2014). The changes in legislation has created a paradigm shift towards a rights based model of care for people with disabilities with supported decision making at the heart of it (Croucher, 2016).

**The importance of ‘Will and Preference’**

From an early age people learn to express an interest or preference to things, make choices, experience the consequences of them and build on their experiences (Peoples First, 2017). Yet, historically for a majority of people with ID, they were not asked what they wanted or given choices. According to research decisions were made by professionals and families in ‘best interest’ and not reflecting the will and preference of the person (Carolan’s, 2018; OPA, 2012). Therefore, many adults with an ID may have difficulty expressing their will and preference/expressed wishes on different areas of their lives due to a lack of choice from living in institutions or services for most of their lives (Burton Blatt Institute, 2014; OPA, 2012).
Services introduced person centred planning such as personal outcomes measures (POMs) which is used by this service. POMs are a very ‘effective in gathering information on a person’s current experiences and identifying their needs and priorities’ (Mc Cormack & Farrell, 2010, P1). This is seen as best practice in disability services as it puts the person in the centre of all decision making regarding what they would want from a service and support they need (Werner, 2012). It focuses on goals people with ID would like to achieve under different areas such as best possible health to living in the community to improve the quality of life of the person (Friedman, 2017). These meetings are yearly, facilitated by a keyworker and attended by close family/friends chosen by the person with ID.

However, a study on providing support for decision making in adults with ID by Bigby, Whiteside and Douglas (2017) highlighted the limiting impact that staff and families had on decision making opportunities for people with ID. They found that staff and families influenced decisions made by adults with an ID to be more in line with an outcome they felt was in the person’s best interest or reduced risk to the person. This was reflected in other research where it was speculated that while the dreams of the person with ID may have been always there, the environment of the person was not one where they could truly express themselves, or actively talk about their dreams. Therefore the goals chosen may not have been a true reflection of what the person wanted (Westthopec and Ball, 2015). Conflict can occur when the will and preference of the person with ID goes against the supporters own interests or beliefs.

According to Peoples First, (2017) supporters should be aware of any conflict of interest and good practice would be to recommend finding an alternative supporter for that goal. Alternatively, to continue to support the person while using reflective practice to ensure the supporter is giving good support by being actively aware of their own biases and not influencing the person with ID (Peoples First, 2017).

Furthermore Bigby et al, 2017 found poor outcomes when staff had to rely on checklists as a source of support to facilitate decision making especially when staff was found to be inadequately trained in communication skills, reflective practice and not realising the undue influence they had on the person. In addition, they identified positive aspects of decision support that supporters needed such as ‘being neutral, managing risk, avoiding influence and not foreclosing options too soon’ (P11).
Also, they highlighted that strategies and resources were needed to develop training for decision making supporters and mentors in these areas. That these strategies should not curtail choice and options available to people with a disability due to focusing on what resources or supports are available or doing unnecessary risk assessments (Bigby et al, 2017).

As research has found that disability services have policies and procedures even protocols that staff need to follow in particular situations, which is operating in the best interests of the service and not necessarily responding to the will and preference of the person (National Disability Authority, 2010). This is acknowledged also by Werner (2012) where he then recommends that staff should provide opportunities to increase skills, attitudes and behaviours of people with ID that exemplifies self-determination. In order for this to transpire changes to attitudes, culture and environment need to happen especially how services are delivered to those with decision making difficulties (Donnelly, 2016; Flynn & Arstein-Kerslake, 2014). Disability services will find it challenging to move from best interest to will and preference due to professional responsibility. However under SASDM care is taken to make sure that the person is fully informed of the consequences of their decisions (Nicholson, 2018). This research will look at this in terms of how SASDM addresses moving from best interest to will and preference and if there is a change in attitudes, culture and environment.

In general, SDM provides opportunities for adults with ID to acquire decision making skills and experience by giving information and support in a way that is accessible to the person so they can make informed decisions and communicate them (Werner, 2012). Furthermore, it encourages family and friends to take on an informal role in assisting the person to make a decision instead of deciding for them (OPA, 2011). However, Croucher (2016) argues that until people with ID can easily express their will and preference they will remain leading a life of someone else’s choosing through the lens of ‘best interests’. This will continue to happen until systems are put in place in services that will support and protect the expression of will and preference and rights of people with ID.
Developing Skills and Knowledge to Support Decision Making

Decision making is a skill that we learn from a young age and one that can be developed through training and development. Supporting someone to make decisions is also a skill that can be developed (OPA, 2012). Also by providing and building on the skills and knowledge of supporters will in effect nourish the decision making abilities of those with ID (Killeen, 2016). Research shows that peer workshops, one to one mentoring and accessible written information for both decision makers and those in supportive roles, was found to be highly effective in supporting decision making in people with an ID (Killeen, 2016). Also it was emphasised that more educative programmes need to be implemented in order for people with ID to be more self-determined. These programmes should incorporate goal setting and self-regulation and adapted to meet the learning needs of the person (Warner, 2012). According to Killeen (2016) small peer workshops which support people with ID to learn what it is to make a decision. Also that resources which have been developed such workbooks and an online decision making tools was found most helpful.

In addition, changes to staff skill set is needed to create a supportive decision making environment for people with ID. The National Disability Authority (NDA) (2018) report on staff competencies and skill mix for a community based model of disability services highlighted the need for staff skills to evolve and adapt to more person centred supports. In order to assist the person with ID to live the life of their choosing. Also, the report highlighted the need to develop new roles in disability services to increase integration in order to build and develop natural supports in the community for people with ID. Furthermore they found that staff who had high expectations of people with ID and encouraged self-reliance had a positive influence on the person’s quality of life. Similarly, it emphasised the importance of staff having the right attitudes to support people to lead a quality life and encouraging positive risk taking (NDA, 2018). In addition self-reflection on one’s own practice should form the basis for resources to train supporters of people with ID about their practice and preferences. Above all strategies and resources are needed for future supporters of SDM, to build co-operative working relationships with all people involved in the DMs life, enabling discussion on difficult topics and to address conflict when it arises (Bigby et al, 2017).
Services need to build positive constructive relationships with families especially when supporting people with ID in decision making on difficult topics (Curryer et al, 2015). The UNCRPD (2006) also recognises the family’s importance and acknowledges the need to support families to assume their role in assisting rights. Due to time constraints families will not be interviewed however will be interesting to see how involved in the SASDM process they are.

**Background of the SASDM Model**

Australia was the first country to pilot supported decision making projects in line with the UNCRPD 2006 and it is based on a strengths based ideology focusing on what the person with ID can do (Killeen, 2016). This fits into the social ecological approach to self-determination for people with ID where the emphasis is on the person’s strengths and not their inabilitys by changing the expectations or characteristics of the environment around them (Walker, et al, 2011). The SASDM model looks at new ways to support people with decision making difficulties to make decisions and looking at what needs to be in place for this to happen (Nicholson, 2016). Other research such as Peoples first (2017) reinforced the idea that it is important for people with an ID and their supporters to remember that not all decisions made, always happen and to acknowledge this upfront. Whereas SASDM sets no limitations to the goals of the person as it is important they realise themselves if it is feasible thus building capacity and problem solving skills.

SASDM aims to assist people with a decision making difficulties set up non statutory SDM agreements in areas of health, accommodation and lifestyle decisions based on the expressed wishes/will and preference of the person with ID (Nicholson, 2013; Westhorp & Ball, 2015). There are many roles under this model such as trainer/mentor, facilitator, decision maker and supporters. The criteria to enter into an SASDM agreement is firstly that the person with ID (decision maker) is assumed to have capacity to make decisions. SASDM uses a broader understanding of capacity and not just the legal definition. This understanding recognises the wish of the decision maker (DM) to engage in the model, their ability to express what decisions they need support with and choose who they wish to support them (Killeen, 2016; Westhorp & Ball, 2015).
Decision makers (DM) are self-selected in South Australia but the facilitators need to undergo an interview and then are chosen by the trainer. Another key area of SASDM is the agreement which identifies the short and long term goals of the DM. They achieve these with the help of supporters who provide accessible information in a format they understand before the DM makes the final decision. The agreement last for six months but can be ended earlier or extended (Nicholson, 2018). Each decision maker has a facilitator who meets with them regularly to develop the agreement and focus on goals that they want to achieve. The role of the facilitator is key to developing the right skills, awareness and approach necessary to support the decision maker to make their own decisions (Killeen, 2016). In addition, SASDM addresses attitudinal and environmental barriers by providing the skills, training and knowledge to those involved in the model to change them (Brayley, 2013).

Facilitators help the decision maker to select a trusted supporter such as a family member or close friend then all participants within the agreement need to sign it (Killeen, 2016; Nicholson, 2018). The agreements also make sure that supporters are involved in the decision maker’s life without taking over (Brayley 2013; OPA, 2011). Facilitators are like coaches to the supporters making sure they have the right skills, knowledge and experience to assist the decision maker to achieve their goals. Then the mentors support the facilitator by building their confidence and skills in meetings and also support DMs especially when conflict is happening to ensure the voice of the person with ID is heard (Killeen, 2016).

Gaps in research were highlighted by Killeen (2016) such as the exclusion of certain groups of people from SASDM such as those with high support needs and low communication ability. There is also little research on the relationship between the facilitators and decision maker supporters in how they build the capacity of people with ID. Researchers have also identified the lack of focus on safeguarding and accountability in SDM projects (Davidson et al, 2018; Killeen, 2016). To which it is hoped this research will address those gaps highlighted. However, in SASDM even though facilitators do not screen potential supporters they can decline to endorse the agreement (OPA, 2011) and part of SASDM safeguards is to have mentors present to support facilitators and decision makers. (Wallace, 2012).
Evaluations of SASDM in Australia

The first SASDM model was first trialled between 2010 and 2012 by the office of the public advocate (OPA) and externally evaluated by Margaret Wallace in 2012. Information was gathered using interviews with participants, supporters and staff from three services. Findings showed increased decision making skills and ability to exercise rights therefore increasing autonomy and self-determination for adults with intellectual disabilities. In addition an increase in support networks and community participation with a positive change in perceptions by supporters and staff in the capabilities of people with ID to make their own decisions (Killeen, 2016; Wallace, 2012). There was clear evidence that SASDM can and has changed people’s lives for the positive (Wallace 2012; Westhorp and Ball 2015. The OPA developed supported decision making (SDM) ‘as a non-statutory element of a stepped model... in which supported decision making takes its place as a less restrictive option than substitute decision making, Wallace, 2012;P6)

The latest evaluation of this project was carried out by Westhorp & Ball in 2015. They carried out focus groups and interviews face to face and via the telephone with those involved in the project. From the research the positive outcomes noted earlier by Wallace (2012) was reiterated in this research also. For the participants there was an increase in ‘goal setting, confidence, assertiveness, reduced frustration and anger and higher level of engagement in the community’ (P70). Also an increase in ‘literacy and numeracy skills, work related skills, change in employment’ and so forth (P 70). For staff there was an increase in knowledge, skills and changed practices with some knowledge and skills diffusion to other people with ID.
Changes were made to the model after each evaluation to enhance its effectiveness for example, in the first trial there was only one project officer to support all people with disabilities in the project. Westhorp and Ball (2015) also found that SASDM works better when the facilitator has contact with the decision maker daily through their work. This has been further developed by training and mentoring facilitators and mentors to apply the model within their disability services. In addition to support facilitators there was a structured debriefing session after each meeting with the mentor which is inbuilt into SASDM process to reflect and plan ahead which facilitators found crucial to the process.

There was many challenges highlighted by both external researcher Wallace (2012) and Westhorp and Ball (2015) such as people with decision making difficulties wanted to be involved in SASDM but did not have anybody to support them. Suggestions were made of getting volunteers to take on this role or even peer supporters who had already been through the process. Peer supporters were trialled as a supporter for a person but it did not work out as they had not known each other before the project (Wallace, 2012). Both OPA (2012) and Peoples First (2017) recognised the deficit of natural supporters and suggested building ‘circle of supports’ around people including volunteers. Additional challenges were in the scheduling and logistics of meetings to limitations of SDM when resources of agencies such as staffing or money affected the fulfilment of goals. Carney (2014) echoed how resources (finances, staffing) in the external environment can affect autonomy of people using the SDM model. Facilitators responded to this by getting independent advocates to provide support in the short term to ensure the person had full information on their rights and their voices were heard (Killeen, 2016).

To fully implement SASDM in the services and an allocation of eight hours per week was made but still found that those on shift work were getting called outside of their working hours. Thus found lead to stress and fatigue for facilitators and they recommended for middle management to be more involved in the process (Westhorp and Ball, 2015). However, supported decision making already has and will continue to positively impact on the way services are delivered to people with an ID in the future. (Donnelly, 2016; Flynn & Arstein-Kerslake, 2014).
Current Study
This research will examine the pilot of the South Australian Supported Decision Making (SASDM) model in a west of Ireland disability service. Twenty one staff from this service undertook an 8 day training (9 days for mentors) in September 2018 with Cher Nicholson (Creator of the model) and Debbie Knowles from Australia. Currently, there are 51 people involved in this pilot; 15 Decision Makers (people with an ID), 15 supporters (People chosen by the adult with ID to support them), 15 facilitators (staff) and 6 mentors (staff). This is the first time the model has been trialled by this amount of people in the one service. This pilot is overseen by the Quality, Enhancement and Development Department within the service. Staff were handpicked from different areas across the service to be a part of the pilot whereas the adults with ID were self-selected.

The overall aim of this research is gain an understanding of what good support in decision making looks like and how this could be developed further so people with an ID can lead self-directed lives. For that reason the research will look at the experience of SASDM within this disability service from the perspectives of people with ID and staff involved in the pilot. Also it will look at the benefits and challenges of using this model within an Irish disability service. Lastly, the research will look at what skills, training and support is needed by people with ID and their closest supporters (including staff), to promote autonomy and decision making skills within a disability service. There has been great success with the SASDM model in Australia and it will be interesting to see if it is transferable to an Irish context. Detailed semi structured interviews will be carried out with three adults with ID, their three facilitators and two mentors (staff).
Methodology

Research Design

This research will take a qualitative design using semi-structured one-to-one interviews applying a hermeneutic phenomenological approach. This methodological approach is interested in the lived experience of people through looking at their attitudes, values, beliefs and experiences (Wilmot, 2005; Whitehead, 2007). Hermeneutic phenomenology is considered as the methodology deemed most suitable for this research in order to gain insight into the subjective experiences of the decision makers, facilitators and mentors who are using the SASDM model. Equally important non-probability purposive sampling method known as maximum variation sampling will be used. Maximum variation sampling looks at the research topic from different perspectives of individuals or groups to gain a better understanding of the area (Etikan & Sunusi-Alkassim, 2016). As the purpose of this research is to gain the knowledge and experiences of three stakeholders involved in the SASDM pilot; decision makers (participants with an ID), mentors (staff) and facilitators (staff) this sampling method was deemed most appropriate. Purposive sampling is non-random sampling, where no underlying theories or a set number of participants is needed. It focuses on the characteristics of the participants and their ability to assist with the research in order to gain thick descriptions of the experience (Etikan et al, 2016).

The use of semi structured interviews emphasizes the significance of the subjective experiences of people (Blaxter et al, 2006). Additionally, semi structured interviews are the most commonly used method of research with people with ID, as the format allows you to guide the interview topics, and adapt the interview to suit the communication style of the adult with ID. This allows for an elaboration of key information that is important to the interviewee and gain detailed insights where needed from the participants (Hollomotz, 2018). Thematic analysis was used to highlight recurring patterns or themes within the data collected and to interpret various aspects of the research topic (Braun & Clarke, 2006). It is regularly utilised in qualitative research. The researcher became familiar with the data collected through transcribing the interviews and was able to assign preliminary codes to the data in order to describe the content. Equally important, was to identify patterns or themes in the codes across the different interviews. After these themes were reviewed then further defined and named resulting in the production of the results.
Sample

The population relating to this research was those participating in the pilot of the SASDM model within a west of Ireland disability service and those that were excluded were known to the researcher to prevent undue influence. Given the short timescale for the study, it was decided to focus on just two groups of people, people with ID (decision makers) and staff in the roles of facilitators and mentors. Semi structured Interviews were done with three decision makers (people with an ID) from three different living arrangements; first person was living in semi-independent living, second person was living in fulltime residential care within the service and the last person was living at home. Their three facilitators (Staff) had two years or under experience of working in the service and the two mentors (staff) had over 15 years’ experience working within the service. Eight interviews was manageable within the short timeframe taking into account the large geographical area they came from. Furthermore saturation was reached after the last interview.

Materials

Prior to starting, the researcher had consulted with the advocacy coordinator with the west of Ireland disability organisation who is also an inclusive research network member. Advice was followed in relation to the information sheets, consent forms and interview schedules for people with an ID to make them user friendly. The photosymbols website (www.photosymbols.com) was used in the development of documents for this research. This website has a library of pictures that are designed to make written information for those with an ID easier to read. Also the Flesch reading score was utilised for this purpose also. The Flesch reading score ranges from 0-100 and higher scores mean the document is easy to read. The documents for this research was in the 80s which according to Datta (2014) was a good score for those with a mild intellectual disability. A letter was drawn up for the gatekeeper (Appendix 1).

Once permission was received from the organisations ethics committee and the gatekeeper, information sheets and consent forms were distributed to the staff (Appendix 4 & 5) and also to decision makers but in an accessible format (Appendix 2 & 3).
The interview schedule was put under headings that were linked to the research questions. Even though there was questions formulated beforehand in this schedule there was room to ask more when something interesting was being discussed allowing the researcher to gain further knowledge on the topic (Appendix 6 & 7). See further for ethical considerations.

**Procedure**

Prior to commencing the research, contact was made with the disability organisation to discuss the possibility of the research taking place. Information sheets and consent form referred to above were developed. Subsequently a letter was sent to the gatekeeper requesting consent to conduct the research and their support in disseminating the information sheets and consent forms to the participants in the pilot. Ethical approval from AIT and the disability service was sought and approved. As a result, the researcher linked in with the gatekeeper in the service to identify decision makers that had different variants of supports already in place such as one living at home, one fully supported by the service and one semi supported by the service to see if this model works in a variety of different settings. In addition their facilitators were targeted for interviews to gain the perspective of both parties about the SASDM model.

The gatekeeper distributed the information sheets and consent forms to the mentors involved in this project. Therefore they were able to identify decision makers and facilitators that fit this description. The mentors in turn contacted their facilitators and decision makers providing them with the information of the research. As a result three mentors identified participants who were interested in the study and two mentors put themselves forward for interview also. With the consent of all participants the gatekeeper passed on the contact details of the facilitators for the researcher to make contact directly. The facilitators in turn organised the interviews with the decision makers.

All three decision makers choose either their place of work or home for the interview to take place. The first facilitator was interviewed by himself and afterwards the decision maker was interviewed with his key worker to support him. This decision maker refused to be recorded and permission was given to the researcher to handwrite notes. However he appeared uncomfortable with the note taking and the researcher stopped taking notes and as a result he positively engaged.
See ethical considerations regarding consent and ascent. Learning from this the next interview was done with both the facilitator and decision maker who supported each other throughout the process and worked really well. Lastly, the decision maker was ok to be interviewed by himself for the first part of the interview and then his facilitator joined in for a group discussion on their experiences. After the interviews was transcribed the findings were emailed to the facilitators to read and discuss with the decision makers for respondent validation and for their approval. Some amendments were made.

**Ethical Considerations:**
According to the National Disability Authority (NDA) (2009), research that includes people with ID should be done in a manner that respects their human rights. In the past, people with ID have been left out of research that concerns them. Therefore it was vital to include people with an ID in this research in order to get the lived experience of the model from their perspectives. In regards to consent it is important to note that part of the SASDM criteria was that participants with ID needed to be capable to give consent and ask for support on the decisions they needed help with. Nevertheless, a number of special arrangements were put in place for the participants with an ID to ensure a process of ongoing consent and assent at each stage of the research. See materials regarding accessible information. Voluntarily participation was sought by giving each person one week to look at the information and consider it, before making the decision to be involved in the research. It was highlighted that they could opt out at any time. A separate interview schedule was formulated for the decision makers and for the staff. Advice was sought from the advocacy co-ordinator of the service around the wording of the questions and what way in particular they should be asked.

The interview schedule was given to the decision makers prior to the interview to allow them time to digest the questions and ease any anxiousness around the interview. The date, time and venue was left to the participants to decide on what suited them best and they choose an environment they were most comfortable with which was either their home or day centre. Equally important, the option to have a supporter present during the interview was highlighted beforehand and one decision maker brought his keyworker. Whereas the other two received support from their facilitator.
Before the interview started a verbal explanation of the information sheet and consent forms was done to ensure they still wanted to participate, that it was voluntary then permission for recording was sought. The consent form was then signed after it was explained and one decision maker requested not to be recorded. Assent during the interview was also looked for and when the decision maker became tired or could not answer the question a break was offered or the question asked in a different manner. The researcher did notice in one interview where the decision maker refused recording that when the researcher was writing notes the decision maker looked uncomfortable and would stop talking. The researcher stopped taking notes to allow the interview to flow better and the decision maker appeared happier as a result. After the interview was transcribed codes were added for confidentially and anonymity reasons. The researcher sent the results to the facilitators to look through it with the decision makers to ensure they were happy with it. As a result small edits were made. A summary of the study will be given to all who participated after it is marked, to those that wish to receive it and it will be put in accessible format for decision makers. Overall, all participants consent was obtained, it was voluntary and they were reminded of their right to withdraw from the study at any time.

Delimitations
Due to time constrictions, word count and a delay in getting ethical approval from the disability service supporters, trainers and an organisations perspective was not included in this research. Furthermore due to the large geographical area of the service only those who were one hour’s drive from the researcher home was included.

Participant Profile
Out of the eights participants there was three female staff and two male staff aged between 30-45 years old and three male decision makers all aged between 25-65 years old. Please refer to sample section for background information on living arrangements of the decision makers and the length of service for the facilitators and mentors. In order to maintain anonymity of staff and people with ID codes were given to each. DM refers to the decision makers and FM refers to the staff and a number assigned based on the sequence of the interviews.
Results

Introduction

The following section will discuss the findings of the qualitative research that was conducted through eight semi-structured interviews in relation to supporting people with intellectual disabilities (ID) to make decisions. To ensure confidentiality codes were used to keep participants anonymised such as DM refers to the decision makers (persons with ID) and FM refers to the facilitators/mentors (staff) involved. The following table (Figure 1), reveals the background of the participants from years’ experience of working in the service for staff to the type of living setting of the DMs.

Participant’s profile

Figure: 1

<table>
<thead>
<tr>
<th>Participant</th>
<th>Codes</th>
<th>Sex</th>
<th>Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1 (Person with an ID)</td>
<td>DM 1</td>
<td>Male</td>
<td>Independent living</td>
</tr>
<tr>
<td>Participant 2 (Person with an ID)</td>
<td>DM 2</td>
<td>Male</td>
<td>Supported Living-residential</td>
</tr>
<tr>
<td>Participant 3 (Person with an ID)</td>
<td>DM3</td>
<td>Male</td>
<td>Living at home</td>
</tr>
<tr>
<td>Participant 4 Staff</td>
<td>FM1</td>
<td>Female</td>
<td>Over 15 years’ experience in the service</td>
</tr>
<tr>
<td>Participant 5 Staff</td>
<td>FM2</td>
<td>Female</td>
<td>Over 15 years’ experience in the service</td>
</tr>
<tr>
<td>Participant 6 Staff</td>
<td>FM3</td>
<td>Male</td>
<td>2 years and under experience in the service</td>
</tr>
<tr>
<td>Participant 7 Staff</td>
<td>FM4</td>
<td>Female</td>
<td>2 years and under experience in the service</td>
</tr>
<tr>
<td>Participant 8 Staff</td>
<td>FM5</td>
<td>Male</td>
<td>2 years and under experience in the service</td>
</tr>
</tbody>
</table>

When the interviews were transcribed the data collected was analysed using thematic analysis and the following themes emerged:

Expression of Will and Preference
Exploring SASDM meetings
Learning and Development for DMs
Learning and Development for FMs
Practical challenges of the SASDM model
Conflict Management in SASDM

Expression of will and preference

A strong theme was the realisation of hopes and dreams and exertion of will and preference by the DMs. This was done by using the skills such as thinking big and unpacking the dream. When the DMs were asked to tell me about their meetings, what they liked about them all three talked immediately about their hopes and dreams ‘I am going on my holidays to America, very excited...to Washington DC....’ (DM2). When asked what he was going to do there ‘go to the white house. Meet all the representatives, democrats...I like politics.’ This was his dream for a very long time to go to America and it was commonly known that he wanted to go. When asked why it did not happen before this ‘I don’t know’. Also questioned was there anyone saying you cannot do this, he said confidently ‘that’s no good. We will make it work’. He invited a local councillor in to his meeting to talk about politics and got invited and attended a council committee meeting as a special guest ‘I was the top businessman’ and an invite to go canvassing with the local councillor. Later, when asked if there was any decisions he will need support with ‘Yeah, with the election, vote for [DM2], to get elected’. At this his facilitator said to him ‘One dream at a time [DM2]’. See more in learning and development for FMs.

DM3 wanted to be a doctor and he joked with his facilitator ‘face on you when I said that’. FM5 said straight away he went into best interest ‘We were trying to solve problems that hadn’t occurred yet’. This dream when unpacked resulted in DM3 wanting to learn first aid and to help his bus driver with the 1st aid box. He has signed up to do a first aid course locally. Also he also wanted to be an actor in Kilnascully but when unpacked, he wanted to be in a comedy show and this wish is still developing. He has signed up with extras Ireland and is getting head shots done as part of his next agreement.
DM3 also wanted to be involved with his local hurling team which was something he would have mentioned in the past but staff overlooked it according to his facilitator but it came up again in his meetings. Also DM3 wanted ‘to build muscles’ which is why he started going to the gym. Originally, it was thought that he wanted to be a personal trainer but when unpacked it was himself that wanted to build muscles not train others. He also wants to work in a sports shop and will be getting work experience shortly. Also he got to go to a disco with his friend in the city which he really enjoyed. More outcomes will be explained further on.

DM1
DM1 spoke straight away about going to a wet wet concert in England with the hope he will get to meet the lead singer which is one of his dreams. FM2 could not believe the detail he had for his dreams. He is also going to San Francisco which was a big dream of his which he didn’t share with the staff. He also wants to meet Mo Salah in Anfield during a champion’s league game. ‘Get him to sign my jersey and get a picture with him’. Another big dream is to go to “a James Bond movie premier, dress up like James Bond and get my photo taken with him’.

Exploring SASDM meetings
Experiences of meetings
For all DMs when asked what they liked the most said ‘I like the meetings’. For DM2 he really loved the way the meetings ran ‘I and [facilitator] do the talking’. When asked was there anything else he liked he replied ‘I like talking business...I like chairing my meetings’. He appeared to really enjoy the business type meetings. Some FMs found the structure of the meetings challenging as it is done in a set format such as no table between them, semi-circle seating, no drinks, no writing during the meeting which some found problematic ‘Difficult thing I found was trying to remember everything as you don’t write anything down’ (FM3). Nonetheless FMs found this type of meeting more effective in getting the DMs to concentrate on what was being discussed. By having regular meetings all FMs felt this was really beneficial in supporting the DMs to make decisions. Decision makers looked forward to people coming into their meeting ‘I like when the people came in to talk to me’ (DM2).
In addition to supporters chosen by the DM they had community supporters also ‘expanding the decision makers experiences and given them all this information’ (FM1). They did this by sharing the things they were interested in during the meeting therefore creating new knowledge or connections. The regular meetings supported the DM to make informed decisions by the accessible information and support on his options.

**Agreements**

Agreements are the contract between the DM and supporters highlighting the hopes and dreams of the DM and where he needs support in the four areas; Health, Accommodation, Lifestyle and Finance. It was highlighted by all FMs the importance of the agreement and how it is worded ‘I want ‘it’s all about I want, and it’s very powerful that they say I want’ (FM1). On the other hand staff would say it is also just as powerful if the DM said no. This is significant as you do not want people to be compliant, ‘you want people to say this is what I want or what I don’t want. It is very powerful that people say No (FM1). When the goals are finalised the mentor, facilitator, supporters and DM signs it. The information is easy to read and explained in a way DMs understand so they can make an informed decision. Clarity is then sought at the end of the meeting, FM1 states ‘you need to clarify to make sure that people understand it and review it… the DM may say I have thought about that and I don’t want or I still want to do that or I didn’t understand something on the agreement’.

When it came to the 2nd agreement it was reported by all that it was so much easier to do. People just seemed to be able to ‘make their decisions more easily as they had been through the process already’ (FM2). These agreements are significant especially when conflict arose between a persons expressed wish and what a supporter wanted for the person as once the agreement is signed by all no one can change it only the DM.

**Methods used to unpack hopes and dreams**

All FMs agreed it was all about having the skills that are taught on the training and using them to find out what the person really wants to do with their life. These skills are transferable from work and outside of it.
Examples of skills (Figure 2)

| Think big principle: you want to go on a plane? Do you want to be a pilot that’s how big you go (FM3) | No opinion, no advice, no nodding or saying you are on the right path/no suggestions (FM2) | Do not get caught in the past or the story. ‘It is about the here and now, into the future’ (FM3) | To actively listen, really listen, to what the person is telling you then support the person not rescue them such as jumping in (FM5) |
| What has to happen to make it happen’(FM1) | Where, what, how repetitive questioning till you find out how they are going to achieve it (FM1) | Let them problem solve and come up with the ideas themselves (FM4) | Silence (FM3) |
Example of ‘unpacking their dreams by picking up on one key word and use repetitive questioning to keep unpacking until they find how they are going to do it. DM1 was ‘big into James bond movies… [Expert] would say dream big…I am the biggest dreamer going…DM3 I want to be James Bond… do you want to be in the movies? No. Ok what about a stunt man like James Bond? No, ok what do you want to do? I want to dress up as James Bond’ (FM2). FM2 notes that through SASDM you are turning it around to the DM to answer the questions. In SASDM, the importance of asking the right questions and unpacking the dream is significant to really find out what DMs want as their hopes and dreams. In addition being creative and exploring many options ‘to unpack and get to the heart of the persons expressed wish of DMs’ (FM2).

**Comparison among SASDM and person centred planning**

SASDM was compared to personal outcome meetings (POMs) throughout the findings. This is similar to person centred planning (PCP). When asking the DMs if they have thought of these goals before in personal outcome they said no. ‘I wasn’t asked or didn’t think much about it then’ (DM1). DM3 said ‘No it’s different… it’s a different type of meeting. Nobody talked to me before about my hope and dreams’. All five DMs spoke about the key difference such as the skills piece, not knowing how to ask the question or not actively listening to the person. FMs found that there was a lot of yes and no answers in doing up the workbook to highlight personal outcomes whereas with the SDM it is very open ended questions. FM2 explained that with POMs it is nearly on the day that the goals are decided whereas with SASDM the person gets an idea in one meeting and then have every two weeks to explore it and unpack it.

**Dreaming big and unpacking the dreams**

‘Only we kept at him to unpack we wouldn’t have known what he really wanted.’

‘You can see someone sitting forward, just chatting about hopes and dreams and it’s all about them, you’re just listening. It’s just that look, it’s just very noticeable. Just brilliant… It is the whole thinking big. The thinking big principle is just fantastic….’

Thinking big ‘if you could go anywhere in the world and money was no object where would you go? ‘It was almost like they weren’t asked that before, the look on their faces’.
FM2 explained that the DMs can change their minds about what’s in an agreement after listening to the information received. It is empowering for DMs ‘that they can change their goals at any time. Unlike personal outcomes where sometimes it was felt that it might not be the reals goals they wanted. SASDM unpacks the goals, gets the information and DMs are informed of options and can change them as you go.

FMs believe the skills from SASDM such as ‘no advice, no opinion and take out the best interest (FM1) and think really big with people. Then that will really change the POMs experience for DMs as they could really complement each other’. Also at POMs meetings it is usually the same people-family, keyworker, staff that attend but with SASDM you invite people in from the community to support the person with their goal. In turn creating more experiences and opportunities for the person while building a support network around them. Also outside supporters were able to do more in certain things were staff were restricted or at a loss as to how to make it happen. The findings highlight the untapped potential and hopes and dreams of the DMs’ I knew this person for years but it never came up in personal outcomes’. (FM3). This was highlighted throughout the realisation of FMs on the unknown potential of DMs.

Learning and development for DMs
Social Roles and friendships
There was an increase in social roles and friendships for DMs. For DM3 he is now a gym member ‘People know him now as he is actually a member of the gym going by himself and not a group from [the service]’. DM2 is now a board member of a performing arts theatre group and also built up a good relationship with a local politician.

Increase Independence skills, motivation to learn and positive risk taking
Findings showed an increase in independence, motivation and positive risk taking in DMs also. DM2 ‘I can make a boiled egg, brown bread and butter by myself’. Also he is creating a recipe book of all the things he can cook. DM3 is accessing his local area independently now ‘I go to the barbers by myself’ and he now goes to other places in the town independently whereas before SASDM he would have had staff support ‘where the support is needed give it 100% instead of little bits of support that’s not needed’.
When given the chance to be more independent DM3 became more self-reliant. He has also become more interested in learning new things and finding out more information by himself.

**Accommodation**
There was changes in accommodation for DM2 who moved into a new home with one of his friends ‘I love living here with my friend’, DM1 is looking forward to ‘living by himself in my own place and have a Jacuzzi’. He currently lives with two others but said ‘It is time to move out as I am the longest one living there’. DM3 was happy to stay at home so had no goals in this area.

**Employment/job coaching**
SASDM has brought positive outcomes in this area also. DM2 has work in an office “I enjoy doing it, it is great’. For DM3 he questioned ‘Why wasn’t I getting paid’ as he had been doing work experience and asked his manager who gave him constructive feedback. As a result DM3 is on a 6 week programme with a job coach to build up his skills and it’s increased his motivation at work. For DM1 had originally wanted to do painting outside but when he thought about it he felt he was too old to get a job doing this.

**Increase in confidence, communication and assertiveness**
The findings showed an increase in confidence, communication and assertiveness for DMs. For DM3 his thinking has changed and he has become more confident and assertive in what he wants. For DM3 there has been an increase in assertiveness, he would now say to his mum ‘Let me off’ if she told him he could not do something. ‘You could see him thinking ‘I am not making a decision I think you are going to be happy with, I am making a decision for myself’ (FM5). FM3 also spoke about seeing the confidence and assertiveness evolving through the process with other DMs. FM3 he was apprehensive about DM1 communication as he found it hard getting information from him in previous meetings. But during the first meeting he was sitting forward, ‘his face was priceless when talking about going to America, thinking of those possibilities, dreaming and not to be shot down’ (FM3). FM1 commented that for one DM she looked great, more outspoken, increased confidence, good humoured and more talkative.
Finance:

Initially this area was a huge concern for all FMs due to the lack of knowledge all DMs had on their own finances. Through SASDM, they have learnt more about their money and keeping it safe. DM1 have learnt how to use and ATM ‘changing the pin to something I remember’. For DM2 he opened a savings account and learning more about managing his money ‘the bills and receipts I bring them into the centre’. DM3 also had poor finance awareness as his parents kept his money safe. But through SASDM he set up an account and has his first direct debit coming from it to pay for his gym membership. DM3 has learnt what responsibility is as it is up to him to have money every month for the gym instead of asking his mum. He is saving more for what he wants and knows he needs money to buy things. For those in mentor roles they highlighted the challenges with families for other DMs involved especially when the DM wanted to learn more about their money.

Figure 3:

Learning needs for Decision Makers

- To know Basic Information-date of birth, doctors name, writing their own name

To learn

- Basic literacy and numeracy skills
- Finance management; keep money safe, pay a bill
- Soft/work skills: Presentation Skills, Meeting skills-greetings, how to present themselves
- How to use a computer and how to research information
- How to use a smart mobile phone and apps/assistive technology to support independence
Learning and Development for FMs

This model has created a fundamental shift from best interest to expressed wish for the staff involved in the pilot. FMs initially found the concepts of how to establish hopes and dreams difficult as it meant a change in work practices for them. ‘I found the training hard I think mostly because I didn’t realise how good at best interest I was (FM1). The out of the box thinking of the trainer, the think big concept and that it was ok to allow DMs to make bad decisions created anxiety at first. However, in SASDM it is not the end goal that’s important it is the journey they go on to reach it or how it may lead to other opportunities for them. ‘No limitations as it is all about the journey’ (FM3). Even by looking into it more the person could change their mind or decide not to do it but it is going through this process that you really find out what they really want. Findings identified a need to ‘build a culture around people with ID that this is their decision’ (FM2). The key skill here is allowing the person to make the decision even if it an unwise decision.

One FM highlighted that they are paid by the service to keep people safe, to ensure activities are done but ‘I think it is going to be hard for staff if there is a wish that jeopardies their job or goes against policy’ (FM2). Even though no one interviewed has experienced this staff acknowledged this situation was covered in training ‘[expert] if issues arise you need to bring in different supports like psychology’.

Another key finding was the positive changes SASDM was having on their work. FM5 gave an example of ‘three people (other people with ID) he supported had independently gone on a bus that day to the city, whereas last year they needed a staff and transport’. This is great evidence of positive risk taking and knowledge and skills diffusion. FM5 stated that ‘Where the support is needed give it 100% rather than giving little bits of support where it is not needed’. Also FM5 highlighted that only for SASDM he may not have fully unearth people’s real goals. It was felt that sometimes due to a person’s past there are risk assessment as with SASDM ‘it is not based on what has gone on before it is based on what is happening now and in the future’. That can be hard for staff to do as they are trained and informed on how to keep someone safe and there are policies, procedures and protocols to follow.
Practical Challenges of the SASDM model

While the feedback of the experiences of SASDM were mostly positive nevertheless there were several challenges at different levels and for some it was dependent on the DM that they were supporting. For those staff who had control over their own time, were office based and supported independent people with an ID they came across little challenges in setting meeting dates, venues and keeping to it. Whereas, when the DMs were reliant on staff, transport or had restricted timetables from within the services challenges presented. Even though FMs tried to stick to the guidelines of SASDM they found themselves having to make changes bringing DMs to meetings, meeting supporters outside meetings. While there was time allocated to SASDM ‘lately I need more hours and I felt four wasn’t enough’ (FM4). Similarly for some people who worked shift work found that even when they were at home they were getting emails or calls out of hours.

While some mentors attended every meeting it was noted that due to the position of one mentor in the service they had other important duties and got pulled away ‘I needed her to be present and she was called to do something else as she has other important responsibilities’ (FM4). In regards to support mentors got to meet regularly discussed challenges faced and offer support to each other, facilitators would have liked this also. Communication appeared to be lacking in a variety of ways, such as other staff not knowing about the SASDM pilot ‘When calling staff and saying DM wouldn’t be in today to his centre as he has his SASDM meeting and people were like. What’s that?’ (FM4). Also, it was found that a lot of managers were very supportive in the beginning but due to miscommunication regarding the amount of time and frequency of meetings, lead to frustration being expressed. FM1 highlighted the need for a forum where staff share information ‘I am doing SDM in this area, I have come across this issue can anyone give me some advice or support around this’. Some FMs felt that an in-depth training manual would be of benefit as a referencing tool throughout the SASDM process and adopted into the cultural of the organisation like polices.

Another key finding was the lack of trusted supporters due to having no family. DMs would have picked staff working with them ‘then you had to explain to them that a supporter was someone that didn’t get paid’. This highlighted the few people DMs had in their lives in an unpaid role.
Conflict management in SASDM

Conflict with the DMs expressed wish and their supporter did arise and many examples were given. FM2 spoke about one family member that was very critical about the DM ‘-you know how you are...you tried it before....’ This is where the importance of the agreement is signified as when the agreement is in place and signed by all, the only person that can change it is the decision maker. ‘They cannot say no to the DM wishes that are in the agreement’ (FM2). In this instance the facilitator needs to ‘remind the DM that this is your meeting and you said in your agreement that you want....’ FM5 explained about DMs mum being very apprehensive about him being a part of his local hurling club. The facilitator acknowledge the mums feelings but then said ‘it was what DM wanted and we need to explore it’. By having the meetings every fortnight appeared to ease the worries of supporters especially when they are apprehensive about the wish.

In addition findings highlighted the need for family engagement. There was no information given to families or training on SASDM in the pilot. It was emphasised by FMs that families need to be involved in the training ‘to avoid an us versus them, explain why we are doing this and get a discussion going where you bring ideas to the table, identify gaps’ (FM5). FM2 spoke about having family/parent role models to learn from or seek advice from them ‘show others experiencing things like DMs wanting to move out or having more control over their money’. With positive role models and a shared learning experience involving families then this will foster and promote decision making for DMs.

Overall, it was clear in the findings that only for SASDM a lot of DMs hopes and dreams would have gone unexplored along with their untapped potential for making their own decisions. There was positive outcomes for all involved in the pilot with some challenges and frustrations that are resolvable.
Discussion

The following discussion is on the experiences, benefits, learning and development gained by DMs and FMs involved in the SASDM model while taking into account the challenges that were faced. Therefore examining whether SASDM is a viable model within an Irish disability service.

Expression of will and preference

The evidence from this research positively shows that SASDM has empowered DMs to voice their will and preference and that their voices were listened to. Overall this research found many great examples of DMs exerting their will and preference and developing their experiences due to an increase in opportunities in many areas of their lives as a result of SASDM. What was an interesting finding was that FMs would have known the DMs beforehand and FMs expressed how difficult it was to get information from them on what they really wanted in life previous to SASDM. However, it was noted that by the end of the first meeting which was called hopes and dreams, there was evident positive changes in body language and engagement in DMs that was not observed by FMs before this. FMs spoke about the untapped potential that SASDM has uncovered in DMs and most importantly will and preference finally being listened to. Some interesting findings to reflect this was for one DM everyone knew he would love to go to America but nothing was ever done about it till SASDM. Another DM had a dream all planned in his head with great detail but never expressed it till he started SASDM. This was a similar finding in Westhorp and Ball (2015) where they speculated that while the dreams may already have been always there, the environment of the decision maker was not one where they could truly express themselves, or actively talk about their dreams. In this research FMs did acknowledged the DMs apprehension about talking about their hopes and dreams initially whilst on reflection they recognised that they were not asking the right questions or actively listening. They also acknowledged that they were operating from best interest by giving their advice or opinion and redirecting DMs to alternatives choices or decisions being made for them. This echoes Carolan’s (2018) research which highlighted decisions being made by professionals and families in best interest and not reflecting the will and preference of the person.
Specifically people with ID who are missing the opportunity to make decision from a young age such as the ability to express an interest or preference to things, make choices, experiment the consequences of those choices and build on their experiences which is more common when they live in institutions or services for most of their lives (Brayley 2012; OPA, 2012; People First 2017). To which, resulted in people with an ID having problems expressing their will and preference and others making decisions for them as a result (Burton Blatt Institute, 2014). However, evidence from this research exhibits positive results of DMs expressing their will and preference, making choices, engaging in positive risk taking and building on their experiences from their engagement in SASDM. This study illustrates this with examples of the hopes and dreams of the DMs such as finally travelling abroad to America to DMs accessing their local community and transport independently to being motivated to find paid work. There has been an increase in their support networks and new friendships formed increasing their circle of support. This research found that the meetings were a huge part of the process in not only building decision making skills in DMs but also in the development of their will and preference in different areas of their lives.

**The importance of SASDM meetings**

One of the highlights noted by all the DMs in the research was the meetings also known as hopes and dreams meetings to the DMs. They valued that the sole focus was on them and their hopes and dreams. DMs ‘loved’ that it was them and their facilitator that did most of the talking. From these findings the meetings appear to be the building blocks of developing a persons will and preference and capacity to make informed decisions. To illustrate, in order to find out what the person really wanted they had to dream big then unpack the dream in regular structured meetings which was found to increase DMs concentration levels in order to get to the core of what the DM really wanted. Through the meetings DMs were given accessible information and support from different people with different skillsets with no undue influence so the DMs could make an informed decision. DMs either agreed or said ‘No’ to which this study highlighted was just as powerful as DMs can be compliant. Then the final decision was with the DMs as to whether or not they wanted to proceed. This reflects the support outlined in the literature under the UNCRPD and ADMA 2015.
Another interesting find was when comparing DMs experience of SASDM meetings to other meetings, personal outcomes meetings (POMs) was mentioned by all which is person centred planning (PCPs) that this service uses to improve the quality of life of the DMs and creates responsive services. As echoed by Friedman (2017) POMs puts the person with ID into the centre of all decision making on what they would want from a service and support they need. However, key differences were mentioned in this research with more favouritism shown towards the SASDM approach. One interesting finding was that the DMs had not mentioned their hopes and dreams in personal outcomes meetings, which FMs found perplexing, considering that this was their platform to highlight them. Furthermore, some DMs believed that POMs was a different type of meeting where they were not asked about their hopes and dreams.

Whereas FMs acknowledged that they were not skilled in getting the right information from the DMs and those at the meeting were operating in best interest which resulted in goals being influenced by staff and families that were not a true reflection of the person really wanted. This was also found by Curryer et al, (2015) that at planning meetings some families can overrule the real decisions the person with ID wanted especially decisions around money, relationships and so forth. This may be due to historically families and services been in control of making the decisions for people with disabilities. According to Werner (2012) caregivers were not always providing the right information and support on decisions to people with ID or gave limited choices due to the need to balance the rights of the person with their professional responsibility. An argument put forward by Croucher (2016) was that unless systems are put in place in services that protect the expression of will and preference and rights of people with ID, then they will continue to live a life chosen by others through the practice of best interest. For some FMs operating in best interest was done with the intention of not having the person upset or annoyed if their decision could not happen.

However, FMs now recognised that the journey to the goal was more powerful for the DM so they could make an informed decision themselves on whether a goal was achievable or not. Other research such as Peoples first (2017) reinforced the idea that it is important for people with an ID and their supporters to remember that not all decisions made, always happen and to acknowledge this upfront.
Whereas SASDM puts no limitation on the DMs so they can realise that themselves. Subsequently thinking of alternatives to goals which promotes decision making and problem solving skills.

**A. Importance of the SASDM Agreement and supporters**

During this research one of the most emphasised aspects of SASDM was the agreement in which the DMs will and preference was embedded in all four areas; Health, Finance, Lifestyle and Accommodation. It also highlights the support the DM wanted in each area. The findings show that these agreements were significant when conflict arose from the expressed wish of the DMs and their supporters. When this happened the facilitator would refer the DMs back to their agreement saying ‘this is what you wanted’. Findings also showed that when conflict arose it was addressed and dealt with in a timely manner due to the frequency of the meetings while also highlighting to the supporters that the DMs have the final decision. Hence, the importance of the agreements which according to the OPA (2011) are for supporters to be included in the DMs life decisions but not to take over thus preventing substitute decision making.

The FMs reported that these agreements were powerful for the DMs as they were making informed decisions based on their will and preference, by receiving accessible information, time and support and experiencing the consequences of their decisions. The supporters present made sure the DMs understood what had been discussed so they were fully informed on the decision to be made. This reflects the enabling conditions Flynn and Arstein-Kerslake, (2014) and Werner (2012) highlighted in the literature which builds DMs decision making capacity and puts them in control over their own lives. It was reiterated by most FMs when it came to the 2nd agreement how easy it was for DMs to come up with goals highlighting the increased confidence in their own decision making abilities.

Furthermore, the findings also highlighted the lack of unpaid people in the DMs lives and the difficulty some FMs found in the pilot to get supporters where there was no family. Both OPA (2012) and Peoples First (2017) recognised this deficit of natural supporters and suggested building ‘circle of supports’ around people including volunteers.
There was apprehension from FMs around the supporters that were not directly family or friends due to whether they would give the time needed to support the person fully. However, it was found that those supporters were incredible in getting things done for the DMs as they were able to access information or support towards a goal where FMs would have been restricted or at a loss as to how to achieve it. This ties in with the NDA (2018) views that outside supporters are invaluable additions to the support network around people with ID due to their different skill sets or information they possess. Furthermore it added the need for staff to build and develop natural supports in the community which SASDM does as this study showed that the DMs enjoyed having other people that came from the community to talk with them. The findings also recognise the role of the supporters which were chosen by the DMs and the importance of picking the right people. Additionally recognising and addressing conflict of interest early in the process so the DM can find another supporter for that goal or the facilitator is aware so they can actively address any conflict in line with the best practice highlighted by Peoples First (2017).

**Learning and Development for DMs**

This research found consistent evidence of positive outcomes for the DMs involved in the pilot such as increase in confidence, independence, communication, finance management, work skills/experience and change of accommodation. Most importantly an increase in decision making capacity and problem solving skills was also apparent. These outcomes were in line with research carried out on SASDM internally by the OPA (2011), and externally by Wallace (2012) and Westhorp and Ball (2015) where they found similar positive outcomes for the participants in their research. There was also evidence of positive risks being taken where one DM was independently accessing town and public transport by himself where last year he needed staff and support. This was done by shadowing and giving information to the DM on keeping himself safe. This is a perfect example of finding ways to enable risk that can cause minimal harm as outlined by Bigby et al (2017). While not focusing on what resources or supports are available, risk assessments (Bigby et al, 2017) or policies and procedures operating in best interest (NDA, 2010) which research suggests can curtail choice and options available to people with a disability.
In this research FMs emphasised the importance of giving the right support at the right time and knowing when to step back. This is acknowledged also by Werner (2012) in regards to caregivers providing opportunities to increase skills, attitudes and behaviours of people with ID that exemplifies self-determination. Interestingly, the most substantial finding was the overall general lack of knowledge DMs had around their finances especially those who were seen as independent. Some DMs did not know where their money came from, how to keep it safe or how to use their ATMs cards. In the findings DMs had gotten support from different individuals from a trusted girlfriend to a taxi driver to access their ATM card which can make the person vulnerable to financial abuse. Though, there was evidence of good practice resulting from SASDM such as DMs learning about finance management and some had opened savings accounts and set up their first direct debit. Nonetheless, if people with an ID are not supported to learn more about their money as highlighted by Killeen (2016) they may have that right taken away from them through substitute decision making. In this research FMs highlighted the challenges with families especially when the DMs wanted to learn more about their money. In the other evaluations of SASDM financial counselling was sought for many of the participants in SASDM which is a free money management counselling programme in Australia to combat this (Wallace, 2012). With the changes in legislation happening in Ireland such as ADMA (2015) issues around finance in particular will be addressed further but for now SASDM, as noted by an FM, is starting to prepare DMs and staff for it. There is a great need to increase DMs experiences in this area thus creating an evidence base of their will and preference and the support they require to make an effective decision. This will be hugely beneficial if and when their capacity is questioned in the future by families or caregivers. Furthermore there was other areas also identified in this research that DMs needed to increase their knowledge and experience in such as the importance of knowing basic information; date of birth, who their doctor is to writing their own name is. As well as how to research areas of interest and education around tools (assistive technology) used to do so such as smart phones and IPADS. Lastly, how to conduct themselves in public.
FMs would like to see DMs doing presentation skills and public speaking training to increase their confidence in exerting their will and preference to others outside their support network. This is echoed by Warner (2012) who emphasised the need for more educative programmes to be implemented that incorporates goal setting and self-regulation and adapted to meet the learning needs of the person. These areas are the basis of decision making capacity as outlined in the ADMA (2015) and UNCRPD (2006) by knowing basic information and retaining it while knowing how to research to gain more knowledge of a certain decision that has to be made. Killeen (2016) found that one to one mentoring, peer workshops and accessible information vital in building skills in people with ID and their supporters. There was no evidence of peer group workshops with DMs or supporters involved in this research.

Learning and Development for Facilitators/Mentors

It was highly evident that SASDM was influential in building the skills needed by the FMs to find out the real will and preference of the DMs in turn building their decision making capacity. The findings show it was the learning gained from thinking big and unpacking the dream that had the biggest impact on the way FMs worked. The recognition that it was not the end goal that was important but the journey DMs go on to realise their goals. Other skills that were equally as valuable such as no opinion/no advice, actively listening, asking the right questions and that it is ok if the DM makes a bad decision.

This correlates to a study by Bigby et al, (2017) which found issues for those providing decision making support to people with an ID such as trying to ‘stay neutral, avoiding influence, managing risk and foreclosing options by being realistic too soon’ (P11). These areas were described by Bigby et al (2017) as perplexing issues for decision support practices and that strategies and resources were needed to develop training for decision making supporters and mentors in these areas. Yet SASDM provides strategies in working through these issues by using the skills taught in the training. These skills if utilised by all staff working in the field of disability, could be seen as the foundation for effective decision making support practice.
Simultaneously, there was evidence that these skills also influenced FMs attitudes towards the decision making ability of DMs with FMs reported to feeling more open minded and creative in supporting the DM in expressing their will and preference. Also, FMs reported that the SASDM skills they learnt had positively influenced their work with other people supported by the service and staff working in the area. They noted that other staff and people with ID were looking to be involved in SASDM as they could see the positive changes happening for the DMs and FMs. This was also a key finding by Westthorp and Bell (2015) where they noted the increased knowledge, skills and changed practices in staff and people with ID with some knowledge and skills diffusion.

In addition to the skills, Bigby et al (2017) emphasised the need for supporters to self-reflect on their own practices and to realise the influence they have in DMs lives. This finding did emerge in this research where FMs became more self-aware of their own values and attitudes that could cause conflict of interest with the DMs will and preference. They noted their heightened awareness of the compliancy of DMs towards staff hence found the new skills helped to address this while also encouraging DMs to problem solve by themselves. FMs also were more aware of their own practice which could lead to disempowerment of the DMs such as jumping to conclusions or talking too much. FMs reported that since SASDM, they have changed the way they support people with ID. In hindsight FMs realised that they would have done things for DMs who were well able to do it for themselves with support and direction thus now they are encouraging them to be more self-reliant and giving them the control. This positively influences the quality of life for people with ID as reflected by NDA (2018) where staff that had higher levels of expectation in people with ID and encouraged them to do things for themselves had better outcomes. This research also found that FMs would like to see SASDM information distributed at induction of new staff as to further create a culture of positive decision making for people with ID going forward.

**Practical Challenges of SASDM**

While the findings of the experiences of SASDM were mostly positive nevertheless there were several challenges at different levels and for some it was dependent on the abilities of the DMs that they were supporting. These challenges were similar to those found in Westthorp and Ball (2015) research.
Firstly scheduling and logistics of the meetings was found to be more of a challenge when DMs were reliant on staff and transport, especially when the supporters increased in number and due to the strictness of a set date and time of the SASDM meeting. As a result this led to changes to the model by staff for practicality reasons such as bringing DMs to meetings or going out to meet supporters who couldn’t attend meetings. Secondly, finding an appropriate venue was hard outside of services especially in smaller towns. Thirdly, allocation of four hours was not enough for FMs as the work grew as the supporters increased. This was highlighted in past research and an increase to eight hours per week was made. Lastly, for FMs that worked shift work found they were getting emails or calls out of hours as people were not available when they were working. This lead to stress and fatigue for facilitators in Westhorp and Ball 2015 research and a call for middle management to be more involved in the process.

A key aspect of SASDM is the supporters chosen by DMs and the outside supporters who give information on their hopes and dreams. The findings underlined the difficulty some FMs had in getting trusted supporters when DMs had no family and would have chosen staff working with them. This is not allowed under SASDM to choose paid staff and this highlighted the lack of unpaid people in some of the DMs lives. This also came up in the research carried out by Wallace (2012) and Westhorp and Ball (2015) where people wanted to become involved in SASDM but did not have anybody to support them. Suggestions were made of getting volunteers to take on this role or even peer supporters who had already been through the process.

Another challenge highlighted by some FMs was getting outside supporters to attend the meetings such as a representative from the bank or travel agent.

Another challenge highlighted was the support given in the timescale of the project. There was meant to be inbuilt systems within SASDM for support to FMs which was seen as crucial in the delivery of quality supported decision making practice.

According to Westhorp and Ball (2015) a structured debriefing session after each meeting with the mentor is inbuilt into SASDM process to reflect and plan ahead which facilitators found crucial to the process. However findings in this research showed that while debriefing sessions happened it was not consistently done across the board.
As Wallace (2012) found that part of SASDM safeguards is to have a mentor present at meetings who acted as a support for both the facilitator and decision maker. However this was not consistently done within this pilot also and facilitators in particular stated they would have liked more peer support or even an online forum to problem solve or support each other. Also it was found that even though there was good support from other managers in the beginning they too were not aware of the timescale of the project and the frequency of the meetings which lead to frustration. There was also an apparent lack of communication around SASDM within the service in general which was challenging when there was remarks from other staff on why they were chosen over them. The process in SASDM in Australia is that staff put themselves forward and are interviewed by the trainer to ascertain their suitability to the training (Westhorp & Ball, 2015). Whereas in this study the trainer did not have the time to interview and people were hand-picked by local managers. Lastly, other staff who worked with the DMs were not told about SASDM and did not realise the importance of the meetings only that it was interfering with their timetables.

**Rethinking Service Delivery**

Evidence from this research shows that SASDM has started a shift in thinking for all those involved in the pilot thus creating strengths based environments for DMs. SASDM model could be viewed as the ‘system’ Croucher, (2016) refers to in protecting the expression of rights and wishes for people with ID in services. Services will need to change to adapt to the new legislation (UNCRPD 2006 and ADMA 2015) along with key policies being implemented in Ireland. From this research there is evidence of the increase in access to society, education and employment which fulfils the standards set out in the UNCRPD (2006). Furthermore the supports systems, structured meetings, agreement, accessible information, time given and allowing the person to decide and take positive risks is in line with ADMA 2015. Therefore SASDM would be a very practical tool in providing specific skills and information to supporters on how to develop or enhance people with ID ‘will and preference’. Therefore increasing their decision making capacity and changing the perception of others on their capabilities which was evident in the findings.
Supported decision making already has shown it can and will positively impact on the way services are delivered to people with an ID in the future. (Donnelly, 2016; Flynn & Arstein-Kerslake, 2014). The findings show that for FMs it has created a fundamental shift from best interest to will and preference as the skills learnt on the training were imperative to finding out what the DMs really wanted. A key finding was that FMs believe that person centred planning (POMs as used in this service) and SASDM could work alongside each other to create a sustainable outcome for the continuity of SASDM in this service. Joining both processes would cause a ripple effect to creating positive supportive environments for DMs to exercise their rights and decision making abilities across the service. As echoed by Werner (2012) that in order for people with ID to exercise their right to autonomy they first need to be allowed to make decisions and be able to communicate them to others. In order to do this services need to implement fully supported decision making practices which would significantly change the way people with ID are perceived by professionals, families and their community.

For this service, FMs believe that if staff developed the skills learnt from SASDM training such as the think big concept and not operate fully in best interest POMs would be more effective. In addition, creating changes to the delivery of POMs such as increasing the frequency of the meetings until DMs have been fully informed on the goals chosen, whilst following the layout of the meeting as this research showed that DMs concentrated better in the SASDM environment. Likewise, having accessible information with open questions in order for DMs to devise a plan on how their goals are to happen was highlighted. Furthermore bringing in outside supporters with similar interests to the DMs goals in order to develop linkages to the community thus building a strong support network for the DMs. Research done by the NDA (2018) highlighted the importance of new roles being developed for staff in services to integrate more into the community such as community connectors. This would benefit the implementation of SASDM model to those without immediate support by increasing the volunteers that may act as future supporters. The outside supporters were seen as a huge benefit of this model for the knowledge and information they brought to the meetings at no extra cost to the service. FMs found that this was one of the highlights of SASDM as they too learnt a lot from these outside supporters and they really helped in supporting the DMs to make informed decisions.
This was also noted by NDA (2018) that by having more supporters in the person with disabilities life in turn it would support paid staff in their roles while increasing the skill mix supporting the individual. In addition families need to be involved more in building the DMs decision making capacity.

Even though this research did not cover the perspectives of the families or supporters it was highlighted by FMs the need for greater collaboration and communication with families. As stated by Bigby et al., (2017) strategies and resources are needed for future supporters of supported decision making, to build co-operative working relationships with all people involved in the DMs life, enabling discussion on difficult topics and to address conflict when it arises. As Curryer et al, (2015) pointed out positive family and staff relationships are very important especially in decision making on difficult topics. The UNCRPD (2006) also recognises the family’s importance and acknowledges the need to support families to assume their role in assisting rights. This research also highlighted the need for role model families for other families to build a peer support structure around difficult topics such as money, housing and so forth. With positive role models and a shared learning experience involving families will further foster and promote decision making for DMs. Thus promoting a culture of positive supportive decision making in all areas of DMs life.

Limitations

- Due to a time delay of six weeks in securing ethical approval from the service the researcher did not have time to get the perspectives of the supporters, families and the organisation overview of SASDM. Future research to encompass all stakeholders in the project.
- SASDM pilot did not include people with moderate to high support needs so it is unknown as to whether SASDM would have similar outcomes for them. Future research needed in this area.
- Due to the large geographical area of the participants, the researcher only did interviews within an hour’s drive from her home.
- The first DM did not want to be recorded and permission received for note taking however the DM appeared uncomfortable during the interview. Note taking was ceased. Therefore limited data collected with direct quotes.
Conclusion

This study highlights what can be achieved when the environment of people with ID is established in a strengths based approach. From this research it was evident that SASDM has been a positive experience for both DMs and FMs. For DMs the unearthing of their hopes and dreams and untapped potential was a significant find. This research highlights what good support in SDM looks like such as the right support given by skilled staff, supportive environments, accessible information, time to process options and allowing for positive risk taking. As a result of SASDM DMs are making their own decisions and becoming more self-determined.

The findings also revealed for FMs there was an increase in confidence, communication, assertiveness, independence skills, work skills/experience, social roles and friendships. Furthermore there was a motivation to learn new things and a decrease in frustration. For FMs there was noticeable changes in their work practices moving from thinking in best interest to will and preference. The highlight for FMs was watching the effect the skills learnt in the training had on DMs and the positive changes in them from the initial meeting when talking about hopes and dreams. Also the learning gained about how their own practices can influence the DMs and how compliant they were to staff. To combat this the skills of thinking big and not foreclosing options too soon, staying neutral, getting the DM to problem solve and allowing positive risk taking were influential in developing their decision making capacity.
Recommendations

The following are recommendations based on the findings from this research.

- SASDM should be continued in the service and information session on SASDM to be rolled out for all members of staff, people with ID and their families and friends to promote positive supported decision making practices. These sessions should be included in the induction of new staff to the service.
- From these information sessions there should be an opportunity for those interested in SASDM to sign up to do the training on the skills involved in the SASDM model including families and close supporters of people with ID to ensure a fully supportive decision making environment for the person.
- To develop peer groups for families consisting of role model families who can provide information and support to other families around increasing people with ID independence in their finances or leaving home.
- To develop a peer mentoring programme of people with ID who have been through the process that they can run information sessions or peer groups for people with ID in their area. Offering support and in the future may become a peer supporter for that person.
- Involvement of role models of the pilot in the deliverance of future training
- Training and education for people with an ID in areas of finance management is paramount
- Further training in personal development and presentation skills for people with ID is needed in order for them to exert their will and preference confidently to others.
- To develop a peer support group or online forum for staff involved in SASDM. In addition enhancing the training manual with clear explanations of the skills and examples on how to use them.
- To increase the hours given to the facilitators from four to eight hours per week or add in additional supports to the facilitators such as key workers so they can answer calls or reply to emails when the person is off.
References:


Appendices:

Appendix 1: Letter to Gatekeeper

1st April 2019.

Dear Ms. XXXX,

Further to our recent conversation I am writing to you request permission to conduct research in the organisation. The study is for my dissertation for my Masters in Advanced Social Care Practice in Athlone Institute of Technology. The title of the research is “Supporting People with Intellectual Disabilities to make Decisions: An examination of the use of the South Australian Supported Decision-Making Model”. My proposed study aims to explore the experiences of the South Australian Supported Decision Making (SASDM) model in order to learn what good support in decision making looks like.

The study has received ethical approval of the AIT Ethics committee and the west of Ireland disability services ethics committee. Please see attached separate information sheet and separate consent forms for both staff and people with an intellectual disability involved in the pilot. As you are involved directly with overseeing the pilot in your organisation I would appreciate if you would act as gatekeeper and disseminate the information sheet and consent forms to all participants. I would be grateful if you could follow up with potential participants after one week and let me know if they would like to be involved.

I would be grateful if you could confirm in writing that permission for this study has been given.

Thank you for your time,

Yours sincerely,

Deborah Brady

A00009070@student.ait.ie
### Information Sheet for Decision Makers

<table>
<thead>
<tr>
<th>Deborah Brady</th>
<th></th>
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<tbody>
<tr>
<td>My name is Deborah Brady.</td>
<td>I am doing a research project as part of my Course in Athlone Institute of Technology.</td>
</tr>
<tr>
<td>I would like to have a chat to you about the hopes and dreams meetings you go to.</td>
<td>I would like to hear what you like and do not like about them.</td>
</tr>
<tr>
<td>You can bring someone to support you.</td>
<td>Please read this information sheet before you decide if you want to take part.</td>
</tr>
<tr>
<td>I would like to record our chat or I can write notes instead if that is what you would like.</td>
<td></td>
</tr>
</tbody>
</table>
- I will get rid of the notes I take and the audio after I have typed it onto a password protected document.

- You can leave at any time and anything you have said to me I can delete up until the 10\textsuperscript{th} April 2019.

- Everything we talk about will be confidential, your name will not be on it or the organisations name.

- The research will be stored in the college’s library.
- I will give a copy to you and your organisation.
- I may talk to others about the findings at conferences within Ireland.

- You have 1 week to think about taking part then Mary Seale will contact you.
• If you want to take part Mary will give me your number and I will call you.
• Please sign the consent form and I will get it of you when we meet.
• I will go through it again to make sure you are happy.

Researcher:
Deborah Brady
A00009070@student.ait.ie

Supervisors Contact Details
Dr. Mairead Seery.
Lecturer in Department of Social Science and Design.
Athlone Institute of Technology
Dublin Rd, Athlone,
Co. Westmeath
0906468275
Email: mseery@ait.ie

Thank You!!!
<table>
<thead>
<tr>
<th>Consent form for decision makers</th>
<th>I have read the information sheet and I know what the study is about.</th>
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<tr>
<td></td>
<td>I have decided to take part in this study.</td>
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<td></td>
<td>I know I can stop at any time</td>
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<td></td>
<td>I agree to the interview being recorded</td>
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<td></td>
<td>I know it will be confidential and my name not given</td>
</tr>
<tr>
<td></td>
<td>I agree that what I have said in the study can be included in presentations or publications.</td>
</tr>
<tr>
<td></td>
<td>I understand all the information above and agree to take part in this study.</td>
</tr>
</tbody>
</table>

Signature: [Your name]

Date:
Appendix 4

Supporting People with Intellectual Disabilities to make
Decisions: An examination of the use of the South Australian Supported
Decision-Making Model.

Information Sheet for participants- Facilitators and Mentors

Invitation
I would like to invite you to participate in this research project which forms part of my
Masters in Advanced Social Care Practice with Athlone Institute of Technology.
Before you decide to take part it is important for you to understand why the research
is being done and what your participation will involve. Please take time to read the
following information carefully. Please contact me if there is anything that is not clear
or if you would like further information. See below for my contact details.

What is the research looking at?
This research will examine the South Australian Supported Decision-Making Model
which is currently being piloted by the BOC in Galway. The research will explore the
experiences of three of the stakeholders involved with the project: people with an ID
(Decision makers) and staff (Facilitators and Mentors). Secondly, the research will
look at the benefits and challenges of this model within an Irish disability service.
Finally, the research will look at what skills, training and support is needed for adults
with an ID and staff, to develop decisions making skills in order for adults with an ID
to lead self-directed lives. This will be done through semi structured interviews with
people with an ID and staff.

What do I have to do to take part?
You will be asked to participate in a semi structured interview at a time, date and
place of your convenience in March 2019.

Why have I been invited to take part?
I am inviting those participating in the pilot to be involved in this research to give their
experience of the SASDM model.
Do I have to take part?
Participation is voluntary so you do not have to take part.

What will happen to me if I take part?
Please contact me on the email address below if you want to participate. You will then need to sign the consent form attached. I will then arrange a date, time and place to meet that is at your convenience in a private area after work. The interview will take approximately 45 minutes. The interview will be audio recorded subject to your permission. All recordings will be transcribed and then the audio deleted. If you do not want to be recorded I will take notes instead. If you decide at any time throughout this process that you no longer want to be involved you are free to leave and have any information you have given deleted up until 31st March 2019.

What are the possible benefits and risks to taking part?
The information I get from this study will help to further understand what good support in decision making looks like and how this could be developed further so people with an ID can lead self-directed lives in line with the United Nations Convention on the Rights of People with Disabilities. It will also give us information on training and supports needed to develop decision making capacity for those with an ID. You will receive a summary of the completed research. There are no risks with this study and it is not expected that the questions will cause any undue distress.

Will my taking part be kept confidential?
Information gathered in the interview will be kept strictly confidential. The information I collect will be password protected on my laptop and identifying information such as the consent forms, will be kept in a locked filing cabinet in the supervisors’ office in AIT. It will only be seen by the researcher and my supervisor. In the research, I will not reveal your name or the organisation you are associated with. At all times there will be no possibility of you as individuals being linked with the data. All information will be deleted on completion of the research and final mark given.
What will happen to the results of the study?
I will produce a final report for my masters and I will give you a summary of the findings if you would like them. The research will be marked and then stored in AIT library. I also plan to disseminate the findings through publication and conferences within Ireland.

If I agree to take part, what happens next?
If you would like to take part please contact me directly on my AIT email below.

Who should I contact for further information?
If you have any questions or require more information about this study please contact me or my supervisor using the following contact details
Deborah Brady
A00009070@student.ait.ie

Supervisors Contact Details
Dr. Mairead Seery.
Lecturer in Department of Social Science and Design.
Athlone Institute of Technology
Dublin Rd, Athlone,
Co. Westmeath.
TEL: 0906468275. Email: mseery@ait.ie
Appendix 5

Consent Form: Facilitators/Mentors

Supporting People with Intellectual Disability to make Decisions:
An examination of the use of the South Australian Decision-Making Model.

Consent Form

I agree to take part in this study on what my experiences of the SA SDM model is. I have read the information sheet. I am taking part as long as I will not be named in the report and my organisation will not be named. I know I can change my mind and drop out of the study if I want to.

Signed _________________________Date ____________

Is it OK with you to have the session recorded? YES_____ NO____

Signed _________________________Date ____________
Appendix 6: Interview Schedule for Decision Makers/People with ID

Introduction

- Thank them for meeting me. Make sure they are comfortable, have a drink prepared and that they are relaxed before starting.
- Confirm if they want or didn’t want a supporter present. If supporter is there get them to go through information sheet and consent form, confirm involvement.
- Explain the process-I am going to ask questions and if you need me to repeat them or ask them in a different way to let me know.
- If they need a break just say it at any time. If they do not want to answer any questions they do not have to.
- Have they any questions for me?
- Start: I just want to see what we can do better to support you to make decisions in your own life. I know you are involved in meetings about your hopes and dreams and I want to ask a few questions about that. Is it ok to start?

Introduction /Experiences of the model

1. I hear you go to meetings with… To talk about your hopes and dreams. Can you tell me about these meetings and how you got on? Prompts: How did you get involved? Was it easy for you to pick your hopes and dreams for your agreements, what kind of decisions have you chosen? Have you tried to achieve these before? Through POMS? Was it easy picking a supporter?

2. Tell me about the kinds of decisions you make in your life by yourself?
Tell me about the kinds of decisions you make in your life with support.
Are there decisions you do not get to have a say in? Get examples on each...

Prompts: Everyday decisions-wear, eat, social activities-meet friends, transport, where you work/live, goals-POMS.

Benefits and Challenges

3. Do you enjoy your meetings? Why? Prompts: What has changed for you since going to the meetings? When you told your facilitator and supporters about your dreams what happened next? Or have you achieved any of your dreams yet? Which ones?
4. What has changed in your life since you started going to these meetings?

5. Every year you and your keyworker meet to do up your goals for the year, are those meetings different to the meetings about your hopes and dreams? Tell me about that? **Prompts:** regular meetings with supporter/facilitator, goals achieved

6. Was there anything about the meetings that you did not like? Like what? **Prompts:** Were you given advice you didn’t want to take? Time it took, goals not achieved fast enough, support not received

7. Do you feel that there are things stopping you making decisions about your life at present? Can you tell me more about that? **Prompts:** home environment, staff support, family support, money, organisational policies/procedures?

8. Can your SDM meetings help overcome these? What help do you need to do these things

9. When you make a decision does anyone try and change your mind? Tell me more about that?

**Skills, Training and Support**

10. What things would you like to learn more about to help you with your decisions? Any training you would like to do?

11. What types of support do you think you need to make decisions? What is good support? **Prompts:** Think of ways you have been supported to make decisions what was really good and what did you not like?

12. Would you recommend SDM to others like your friends/colleagues in the services

13. Is there anything else you would like to tell me? Any questions you would like to ask?

**Finish:** Thank them again for taking the time to meet me. Explain that I will type up what was said and I will ring or meet them to make sure they are happy with what was said. If they think of anything else afterwards that they forgot to say that they can contact me up until 31st March.
Appendix 7: Interview questions for the Mentors and Facilitators (Staff).

Introduction: Thank them for their time. Go through Information sheet and consent form. Explain the process and ask if they have any questions.

Experiences of the model

1. Tell me about you; what is your position within this organisation. How long you have worked in this area. Professional background/Education.
2. Tell me about your experience of the model? Prompts: How were you selected for this pilot, your role within it? What do you like about the model and what would you change?
3. What is the SDM process- selection of decision maker, selection of supporters, and frequency of meetings and accessibility of getting to meetings, how long do meetings last?
4. Tell me about the first agreement and the 4 sections- Health, Accommodation, lifestyle and Finance. Process of working on dreams-unpacking the Dreams, the importance of guests coming in to give information or support to achieve the dream, what happens after the first agreement time of 6 months is up?

Benefits and Challenges

5. What are the benefits of using this model? How has the model changed the way you work with people with an ID? Prompts: Attitude, behaviours, personal boundaries, way you see the person with ID.
6. Do you notice a difference between the SDM meeting and other meetings you have been involved in with people you support? Prompts: personal outcomes- Is there a difference? Difference key worker and facilitator? Skills needed
7. What is going good for your decision maker and what things would you change for them?
8. What are the limitations of this model in a disability service environment? Prompts: resources, staffing/transport to meetings/lack of support on decisions by families/staff, service policies?
9. If conflict arouse between what the expressed wish of the person was and their supporter or staff how would you handle this?
10. What skills, knowledge and experience do you think is needed to be an effective facilitator/Mentor?

Skills, training and support needed for people with ID and staff to develop decision making capacity

11. What support did you receive in your role as mentor/facilitator? Was it sufficient? In what way would you like to see support given to those in this role?

12. What were the highlights of the training and what were the key skills they learnt? Any improvements you would make? **Prompts:** What training materials were you given? What was hugely beneficial and what needs to be developed further?

13. What training would you like to receive to develop your skills and knowledge in this area? **Prompts:** What type of training materials need to be developed further or changed to work better?

14. From your experience of the model what supports do you think people with an ID need to make decisions? What skills, information, and training would you like to see for them?

15. Would you recommend this model to your colleagues and the people you support?

16. Do you have anything else you want to add?