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Dissertation

***Exploring informed choice in the context of self-directed support
for disabled young people in transition: A qualitative study***

Declaration of originality

I hereby declare that this dissertation has been composed by me and is based on my own work.

Abstract

Self-directed support (SDS) is a major policy initiative introduced by the Scottish Government to promote personalised services by redefining the relationship between the citizen and the state regarding social care supports. Informed choice is one of the underpinning principles of the *Social Care (Self-directed Support) (Scotland) Act 2013*.

Transitions between children's and adult social care services for disabled young people are recognised internationally as being challenging for the young person, their families and services. This dissertation will explore the phenomenon of informed choice in relation to the policy of self-directed support for disabled young people in transition from child to adult social care supports.

The theoretical approach to the research study is that of critical realism and in particular *realistic evaluation*. The research involved multiple qualitative methods involving secondary analysis of qualitative longitudinal interview data, and primary interviews with a range of stakeholders. The study developed middle-range theories and hypotheses concerning the facilitators and barriers to informed choice for disabled young people in transition.

Self-directed support is entering the implementation phase of the policy cycle in Scotland and this study will inform emerging policy, practice and future research in self-directed support for disabled young people in transition.

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1. Introduction and Background to the Research

One of the challenges for social care in Scotland is the increasing number of young people with complex disabilities and high support needs who are making the transition from children's to adult services (Social Work Inspection Agency, 2010). Transitions are nationally recognised as being problematic for agencies and frequently lead to poor outcomes for disabled young people and their families (Scottish Government, 2011).

Self-directed Support (SDS) is seen as the means by which individuals and families can have informed choice and greater control about the way support is provided to them. The *Social Care (Self-directed Support) (Scotland) Act 2013* passed by the Scottish Parliament, and likely to be brought into force sometime in 2014, places a duty on local authorities to have regard to five general principles: *involvement, informed choice, collaboration, respect, and participation in the community* to promote increased personalisation in meeting the social care needs of adults and children. The Act seeks to ensure that adults and children are given more choice and control over how their social care needs are met, and those individuals and their carers will require information and advice to make informed choices about their care (Payne, 2012).

Choice plays an important role in a person's quality of life (Smyth & Bell, 2006). However, people with learning disabilities frequently report a lack of choice and control regarding many decisions, including not being given a choice in who provides formal social care support (Bond & Hurst, 2009). Disabled young people with cognitive and communication difficulties face additional challenges to meaningful engagement in decision-making (Murphy & Oliver, 2012). There is a gap in the literature regarding how informed choice is realised in the context of self-directed support for disabled young people in transition.

The dissertation will explore the principle of *informed choice* in relation to disabled young people in the transition between school and adult services requiring ongoing formal support to meet their social care needs. This research has the potential to

benefit policy-makers, managers and practitioners from across health and social care by increasing the understanding of the facilitators and barriers to informed choice. The timing of this research is particularly pertinent as the Scottish Parliament recently passed the *Social Care (Self-directed Support) (Scotland) Act 2013*, and local authorities and others are preparing for it being in force sometime in 2014.

Transitions for young disabled people and their family carers

Transition from child to adult services is internationally recognised as being problematic, frequently due to a lack of co-ordination between adult and child services (Cheseldine, 2010; Mansell, 2010). Where children's and adult services do not work collaboratively, at transitions young people and carers have high needs for information (Allen et al, 2012). Parents are said to find transitions difficult and stressful (MacIntyre, 2009).

There are concerns about the lack of involvement of young people in the transitions planning process. It is often assumed that because of communication difficulties and impaired intellectual capacity, the views of people with learning disability are either irrelevant or inadequate (Smart, 2004). This can lead to children's and young people's issues being identified and resolved by parents and professionals (Davis, 2011). In the absence of the client voice, the views of professionals and family carers can determine the transition agenda (Kaehne & Beyer, 2009).

While the views of parents and other family carers are often accepted uncritically as being a proxy for the voice of the young disabled person, this is a problematic area. For many the term 'carer' (when referring to parents) is ineffective in that it can be seen to depersonalise the relationship between parent and child and turn a normal human experience into a quasi-professional role that contains an implication of burden (Molyneaux *et al*, 2011).

Issues of empowerment, rights and responsibilities for disabled young people at transition have received little attention in the published literature (Tarleton & Ward, 2005). However, a qualitative study involving six young people with learning

disabilities which explored the perspectives of this group on their transition to adulthood, focusing on the process of negotiating autonomy within the family, found some evidence that those young people who were supported to take on valued roles and responsibilities had an improved experience of transition (Mill *et al*, 2009).

While some research studies focus on young people with specific disabilities (e.g. learning disability or specific health conditions) this study will include all young people who have a disability which necessitates them requiring ongoing formal social care supports.

Self-directed Support (SDS) in Scotland

SDS is at the centre of the Scottish Government's agenda to promote personalised services. The Bill for the *Social Care (Self-directed Support) (Scotland) Act 2013* was passed by the Scottish Parliament in November 2012 and received Royal Assent in January 2013. It is expected that Scottish ministers will bring the Act into force sometime in 2014.

Internationally self-directed support and personalisation are seen to be the basis of a reconfigured relationship between the individual and the state which draws on a view of individual and community strengths working in partnership with local agencies (Glasby, Duffy & Needham, 2011). Scotland has decided that SDS should be less focused around the individual budget and more about the relationship between the individual and the state, as was explained in the author's recent interview with a Scottish Government SDS policy maker:

We wanted our policy to be primarily about values and principles that underpin self-directed support. [...] it is about social care returning to what it should be about for professionals [...] and the individual having more control and say.

Individuals assessed as having social care and support needs can choose to directly manage their individual budget, or they can decide to take less direct control by asking the local authority to arrange support on their behalf. The Act provides four

options for self-directed support for individuals who are assessed as needing care or support:

1. The local authority makes a direct payment to the supported person in order that the person can then use that payment to arrange their support.
2. The supported person chooses their support and the local authority makes arrangements for the support on behalf of the supported person.
3. The local authority selects the appropriate support and makes arrangements for its provision.
4. A mix of options 1, 2 and 3 for specific aspects of a person's support.

There is no universally accepted definition of self-directed support and the term can be seen to be evolving to reflect changing emphases in policy. The difficulty in agreeing a clear definition for SDS is evident from a review of SDS commissioned by the Scottish Government which states that the many descriptions are unclear and use terms such as choice and control interchangeably (Manthorpe et al, 2011).

The Scottish SDS legislation and associated guidance provides five principles that will guide everyone when they use the new law: involvement, informed choice, collaboration, dignity, and community participation. In terms of the principle of informed choice, there is a duty on local authorities to provide a person with assistance to make an informed choice when choosing an option for self-directed support.

Informed choice

A person must be provided with any assistance that is reasonably required to enable the person: a) to express any views the person may have about the options for self-directed support, and; b) to make an informed choice when choosing an option for self-directed support. (Payne, 2012, p. 19)

Disabled young people confront not only the everyday challenges of growing up and moving from school to further education and employment, but also the challenges of moving from children's to adult social care and health services. Giving people choice is seen as the key to personalisation (Jenkins & Hay, 2010). People with learning

disabilities in nine EU member states said that having choice and control in their lives was essential to their sense of personal well-being and belief that they had a future (European Agency for Fundamental Rights, 2012). Research on the experiences of disabled young people who are leaving school has focused primarily on the parent-professional interface and their experiences of statutory processes. Little is known about the decision-making processes that take place within families when a disabled young person is in transition (Maddison & Beresford, 2012).

The assumption that adults are rational beings provides the intellectual foundation for most public policies in Western democracies, promoting the individual's right to choose, unless the choice harms others. However, behavioural psychology research has found that choice involves both rationality and intuition (Beresford & Sloper, 2008). Rationality is based on considering the available information, while intuition is framed by past experiences and associative memory. Kahneman (2011) highlights that we like to think our decisions are based on rationality, but our intuition is often a more powerful determinant of choice. In addition, choice should not be considered as a discrete event as it involves a process of locating the issue within the individual's social context, collecting relevant information leading to a decision, and reflection and review following the choice being made.

Choice has emerged as a key concept for the reform of public services and is seen as a cornerstone of SDS in Scotland. Having choice is seen as important in improving health and promoting independence (Baxter *et al*, 2011). Choice is also regarded as a lever for changing the power base of relationships between individuals and care services (Stevens *et al*, 2011). However, choice is not an unproblematic concept and can involve conflicts in three areas: conflicts over inequalities; conflicts over power; and conflicts over the relationship between public and private (Clarke *et al*, 2007). To summarise Clarke *et al* (2007): choice mechanisms in public services can firstly replicate social and economic inequalities where those with more social capital (e.g. education, wealth, social networks, etc.) can more effectively achieve desired outcomes. Secondly, there is an antagonism between choice and power, in that professionals retain power over eligibility criteria and identifying how needs can be legitimately met. Thirdly, there can be conflict over the relationship between

public and private, where services have to deal with multiple and competing demands from individual 'consumers' within finite resources.

Information of good quality, given at the right time, in the right format is seen as a precondition for choice (Baxter & Glendinning, 2011). Informational continuity was found to contribute to smooth transition from child to adult services for young people with diabetes (Allen et al, 2012). Professionals have a role in providing relevant information to service users by targeting information and developing personalised information systems (Baxter et al, 2008). However, research into health screening programmes concluded that the evidence that written information promotes informed choice is unconvincing, and that the definition and measurement of *informed choice* is problematic (Fox, 2006). Services may not be providing information in a format that is keeping pace with trends in the way that people access information. However, the use of the internet for health and care services may not be commonplace; for example, despite the increasing proportion of the population that use the internet, the use of online information for healthcare choices is relatively low (Radha et al, 2012).

Research commissioned by the Social Care Institute for Excellence in England found that for young people and their families at transition there was little information made available to support young people to be in charge of their lives (Tarleton & Ward, 2005). There is a similar lack of accessible information in Scotland for disabled young people and their families about supportive services during transition (Scottish Transitions Forum, 2013). There is also limited evidence of the involvement of disabled young people in decision-making regarding their social care (Franklin & Sloper, 2006). A qualitative study of disabled young people with degenerative conditions found that the processes of choice-making are diverse and that choices are often shared with other people, especially parents and peers (Mitchell, 2011).

Choice and control are seen to increase the ability for people to make positive changes in their lives and to achieve desired outcomes (Glasby & Littlechild, 2009). However, choice can be a problematic concept, with the process of making choices sometimes causing negative emotions such as fear, worry and stress (Baxter, Rabiee & Glendinning, 2011). Many choices take the form of a choice between

retaining the status quo and accepting an alternative to it which has potential advantages and disadvantages. Kahneman (2011) has demonstrated that where there is a possibility of loss the decision maker will be biased in retaining the status quo. For disabled young people in transition retaining the status quo is not an option as school, health and social services set age criteria which are not negotiable, but it is possible that in times of change parents will prefer the option closest to the existing status quo.

A study of the decision-making preferences of adolescents with chronic illnesses in medical decision making found that the largest proportion of adolescents preferred a passive approach compared to active or shared decision-making (Knopf *et al*, 2008). It may be that different preferences are expressed when it comes to decisions about social care services. A study of advocacy for disabled children and young people found that they have a view, can be assisted to express their views, and can contribute to complex decision-making processes if supported through advocacy (Franklin & Knight, 2011).

The review of the literature on SDS, informed choice and transitions for disabled young people illustrates the complexity of understanding how emerging policy initiatives are enacted by local agencies and the impact on the people the policy is designed to help. Existing research findings and acknowledgements of gaps in our knowledge have shaped the design of this exploratory study by addressing the research questions outlined in the following section.

2. Research Design and Methods

A research design is a plan for collecting evidence that will be used to answer a research question. Selecting the design is the most important choice in planning a research project, because it determines all subsequent choices of methods. The design should be selected principally on the basis of how well it addresses the research question and enables the researcher to resolve a research problem. (Vogt, 2008, p. xxiv).

The aims of the research study were to explore the phenomenon of informed choice for disabled young people in transition to adult services/supports. This information has developed our understanding of informed choice in the context of self-directed support, especially with regard to perceived facilitators and barriers to informed choice.

The research strategy was based on a two phase qualitative exploratory sequential design. The first phase involved the secondary analysis of qualitative longitudinal data with the aim of identifying key themes that were used to inform the research questions for the primary stakeholder interviews. This strategy allowed the researcher to further explore the phenomenon of informed choice with a range of stakeholders to elicit multiple perspectives and identify emerging theories. The study explored the phenomenon of informed choice and has begun to develop broad hypotheses ('folk theories') based on the accounts ('folk wisdom') of key participants.

Theoretical approach

"To ensure a strong research design, researchers must choose a research paradigm that is congruent with their beliefs about the nature of reality."

(Mills et al, 2006)

My own ontological and epistemological position is best represented by *critical realism* and the chosen research design is influenced by *realistic evaluation* (Pawson & Tilley, 1997). Realism accepts that there exists an objectively knowable, mind-

independent reality, whilst acknowledging the roles of perception and cognition. Critical realism aims to identify structures that generate the social world in order to challenge inequalities and injustices. Advocates of critical realism describe it as the 'third way' beyond the limitations of positivism and interpretivism (Bergin *et al*, 2008). There are also claims as to its 'double inclusiveness':

"[...] critical realism is [...] the ontologically least restrictive perspective, insofar as it is maximally inclusive as to causally relevant levels of reality and additionally maximally inclusive insofar as it can accommodate the insights of other metatheoretical perspectives." (Bhaskar & Danermark, 2006, p. 294)

Realism seeks to position itself as a model of scientific explanation which avoids the traditional epistemological poles of positivism and interpretivism. The researcher needs to be able to move between the different research paradigms in response to the situation. Realism's key feature is its stress on the mechanics of explanation. Critical realism is an integration of realist ontology (there is a real world that exists independently of our perceptions and theories) with an interpretivist epistemology (our understanding of this world is inevitably a construction from our own perspective). Some realists describe their approach as being neither inductive or deductive, but 'retroductive' in that realists ask why things happen including the impact of the researcher on the production of the data (Olsen, 2007).

Realistic evaluation argues that it is not 'programs' per se that 'work'; rather they contain certain ideas and resources which work for certain individuals in certain situations, and it is the task of the researcher to test theories to identify what works for whom in what circumstances. The basic model is: **Context + Mechanism = Outcome**. The realist evaluation cycle starts with *theories* about how mechanisms are fired in contexts to produce outcomes; specific *hypotheses* are derived from these theories in terms of what might work for whom in what circumstances; these hypotheses are tested through *observations*; and these observations lead to empirical generalisations (*program specification*) about what actually works; and these feed back into theory refinement (figure 1).

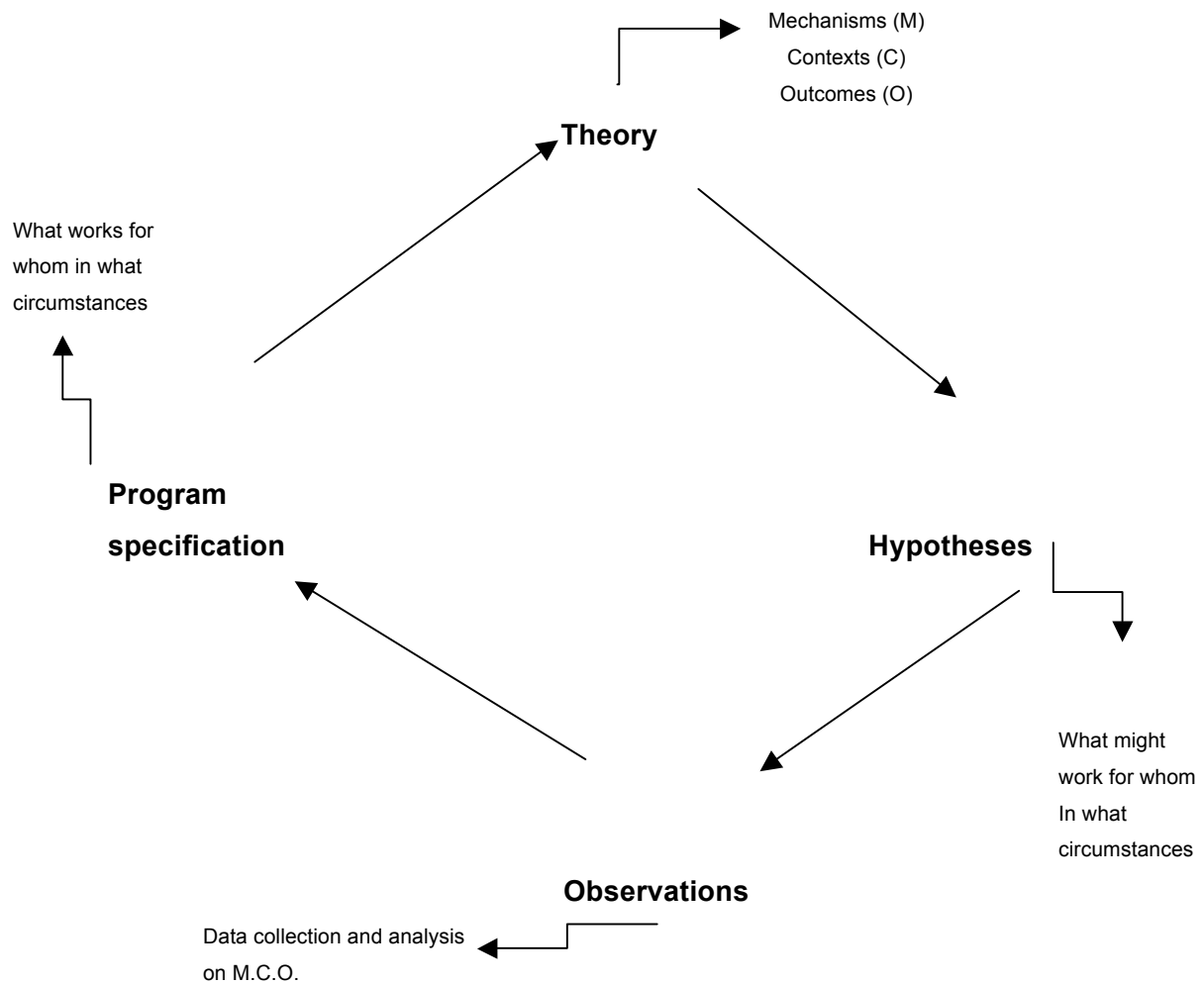


Figure 1: *The realist evaluation cycle* (Pawson & Tilley, 1997, p. 85)

Realistic evaluation suggests outcomes are characterised by the equation: **C (Context) + M (Mechanism) = O (Outcome)** and seeks to answer the question ‘*what works for whom in what circumstances?*’ (Pawson & Tilley, 1997, p.109). ‘Realistic evaluation’ is not an evaluation technique as such, but is a framework for programme evaluation (Pawson, 2002). Realistic evaluation can be used with any legitimate research method: both quantitative and qualitative, and does not favour any one technique (Pawson & Tilley, 1997).

The importance of social context in understanding how complex programmes lead to changes in outcomes are emphasised in realistic evaluation (Blamey & Mackenzie, 2007). People generate change in social contexts through their actions on the basis of their interpretations, capacities, and liabilities (Bonner, 2003). This approach to

programme evaluation engages stakeholders in the generation and ownership of theories, requiring a more intensive relationship between researcher and stakeholders than would be found in other some other approaches.

Pawson & Tilley (1997) do not refer explicitly to *grounded theory* in their work, but this approach, which attempts to explain as well as describe, can be seen to have influenced realistic evaluation.

The theoretical approach adopted for this study is in many ways closely related to constructivist grounded theory, but with some distinct differences:

1. Grounded theorists use theoretical sampling whereas I have sampled on the basis of including all the significant stakeholders in informed choice and self-directed support for disabled young people.
2. Constructivist grounded theorists state that all reality is socially constructed whereas critical realists accept that there is an objective reality but we do not have direct access to it.
3. Grounded theorists tend to use memos (notes) rather than retrospectively study interview transcripts in detail.
4. Coding for grounded theorists is emergent and interactive, whereas I have coded after the interviews were completed: emergent but not interactive.
5. Realistic evaluation uses the *teacher – learner* approach with the researcher articulating his/her theories to interview subjects and asking participants to share their own theories ('folk wisdom') and refine or refute the researcher's theories.

Realistic evaluation is based on theory-led evaluation and such approaches have become increasingly popular way to study partnership evaluations (Dickinson, 2006); with a *Theories of Change* approach increasingly espoused as an evaluative approach to policy initiatives (Sullivan & Stewart, 2006). Both 'theories of change' and 'realistic evaluation' emphasise the importance of programme context in understanding how complex programmes lead to changes in outcomes.

Pawson & Tilley (1997) explain that all social programmes are introduced into pre-existing social contexts made up of social rules, norms, values and

interrelationships. A key distinction between the two approaches is their interaction with stakeholders: in theories of change approaches, the theory is ideally articulated, owned and approved by a wide range of stakeholders; while the realist evaluator articulates the theory through interviews with a more limited selection of stakeholders, but retains control of the theory (Blamey & Mackenzie, 2007).

The research study on which the dissertation is based has included all four categories of key stakeholders distinguished by Pawson & Tilley (1997): *subjects*, *practitioners*, *evaluators*, and *policy-makers*. Each stakeholder group has valuable but partial knowledge and experiences of the phenomenon and it is the researcher's task to draw on these diverse perspectives in order to refine concepts and develop theories.

[...] the goal has never been to construct theory per se, rather it has been to develop the theories of practitioners, participants and policy makers.

(Pawson & Tilley, 1997, p.214)

Research questions

Given that self-directed support is a recent policy initiative with a lack of an established practice or research literature base, the research questions themselves were open and with the flexibility to explore emerging topics as the interviews progressed. Qualitative research questions were focused on developing theories from stakeholder's knowledge, attitudes and experience. Core areas were asked of all participants, such as what they consider to be the facilitators and barriers to informed choice, and some specific questions were asked of individuals depending on their role in the process. As an exploratory study the interviews were semi-structured with fairly open questions to allow the researcher and participants to explore topics as they arose. The research questions were broad and based around who influences informed choice and what are the key factors in disabled young people's decision-making:

- *What information and assistance is available to disabled young people in making choices?*
- *Who is involved in assisting disabled young people with informed choice?*

- *What are the facilitators and barriers to informed choice for disabled young people?*

Data collection methods

The study used a multiple qualitative design consisting of two strands with sequential timing: firstly secondary analysis of interviews held with disabled young people and their parents, and, secondly, primary research interviews with a range of stakeholders in Scotland.

1. Secondary analysis of interviews with disabled young people and their parents

Secondary analysis is a key research council funding priority in the UK as it is seen as a way of maximising the utility of existing research in a time of financial constraint. Secondary analysis can be defined as the (re)using of data produced on a previous occasion to glean new social scientific and/or methodological understandings. The re-use of previously collected qualitative data can, according to Irwin & Winterton (2011a), be carried out to:

- assess the credibility of new research
- supplement one's own primary data
- reveal new methodological insights
- provide rich descriptive information
- generate new findings
- gain further insight on hard to reach populations without further intrusion into vulnerable populations

Secondary analysis should not be considered an easy option when choosing a research method:

Secondary analysis is a challenging undertaking. It is time consuming. It requires great persistence in ensuring an adequate understanding of details which may be tacit for primary researchers. [...] However, as many insightful secondary analyses stand testament, there is a depth of social scientific insight and progress which can be achieved. (Irwin & Winterton, 2011c, p.14)

Debates on the challenges of secondary analysis tend to be focused on two methodological issues: the original data not fitting the new research questions, and the lack of direct access to the detailed contextual knowledge about the circumstances of the data collection possessed by the primary researcher (Coltart et al, 2013).

Interview data from the Social Policy Research Unit, University of York: *Choice and Change: extending choice and control over the life course – a qualitative longitudinal panel study* were added in 2012 to the ESRC *Timescapes* archive hosted by the University of Leeds. *Choice and Change: extending choice and control over the life course – a qualitative longitudinal panel study* examined the realities of choice in the context of changing circumstances, including changes in illness, disability or social transitions (Mitchell, Maddison & Beresford, 2011). The original Choice and Change study included 27 disabled young people with degenerative conditions and their parents and focused on the processes by which choices are made within families, exploring the respective roles and experiences of young people and their parents. Data from 20 of these 27 cases were archived with Timescapes

Irwin & Winterton (2011b) caution against sampling from within project data sets as there is a risk that this further decontextualises data. However, with regard to my own research questions it seemed relevant to limit the cases included to have some commonality in terms of a statement of special educational need (SEN). An SEN is applied in England to children and young people with a learning disability who require additional help at school. Only individuals were included in the sub-sample where both the young person and their parent(s) interview transcripts were archived. This left a cohort of 6 disabled young people and their parents (mainly, but not exclusively, mothers) to be included in the secondary data analysis. One case consisted of two young disabled people from the same family, resulting in 6 disabled

young people and their parents included in the sample from 5 households (table 1). The following table presents a pen picture of each individual. All the young people were White British, and all families had access to a car.

Table 1: Details of study participants:

Study ID	Gender	Age at first interview	Communication difficulties	Mother's marital status
YP-008	Male	14	Yes	Married
YP-019	Female	21	No	Single
YP-020	Male	21	Yes	Married
YP-026	Male & Female	21 & 19	Yes	Married
YP-032	Male	17	No	Married

2. Interviews with stakeholders

Semi-structured interviews were held with a range of stakeholders including a policy maker from the Scottish Government SDS team, the co-ordinator of a national transitions forum, and a number of people from 'Urbal Region' (an anonymised region of Scotland with a mix of urban and rural population), including a disabled young woman, a third sector manager of support services, a manager of an independent college providing residential and day support for young people with learning disabilities, a social worker, a social work manager, and an independent consultant with experience in SDS and participation for disabled young people.

Urbal Region was selected as an appropriate location for the research interviews as a region with a mix of urban and rural settings, and because it was a Scottish Government test site between 2010 and 2011 for self-directed support for disabled young people. *Purposeful sampling* was used to recruit participants in that a 'gateway' professional contact in Urbal Region was asked to identify suitable participants representing the range of stakeholders involved in transition planning for

disabled young people. Relevant national stakeholders were identified and approached directly by the researcher. The focus of the stakeholder recruitment was on recruiting both 'active stakeholders' who influence the policy at different stages, and 'passive stakeholders' who are affected by the policy (Hanberger, 2001).

Semi-structured interviews offered the advantages of a degree of shared focus across the interviews with predetermined topics to be covered, but also allowed scope for flexibility to pursue certain subjects in greater depth. Informed consent to participate was gained from all the subjects and all interviews were audio recorded on a digital recorder. Transcripts of the interviews were written on *word* documents on a personal computer by the researcher. These were anonymised, in that the name and locality of the participant was not stated. The interviewees' professional background or role was tied to the transcripts for analysis purposes. Any subsequent publications will ensure anonymity by not identifying participants by name or indicating the geographical region in which the research was carried out.

The potential risks or hazards in terms of data collection are limited but included the loss of the digital recorder containing recordings of interviews. The substance of the recordings is considered to be of low risk in terms of any data protection issues or potential harm to the interviewees. Risks of loss of equipment were mitigated by keeping the digital recorder in a locked briefcase and written records are kept in a password protected personal computer. Transcripts will be deleted after a period of 6 months.

Other data collection methods were considered: *participant observation*, *documentary analysis*, and *focus groups* but these methods were not pursued on the basis of ethical and pragmatic grounds. Firstly, *direct observation* (either as a participant or non-participant) is a standard ethnographic method that can be used to understand behaviours such as the interaction between practitioners and service users. It is argued that behaviours are more stable over time than are attitudes and opinions (Gobo, 2011).

Secondly, the use of *documents*, such as minutes of transition planning meetings, could offer a unique perspective on the study phenomena in terms of their content and how they are manufactured (Prior, 2003). For example, a study of the minutes

of transition planning meetings could reveal patterns of who attends such meetings, the issues discussed, whose 'voice' is recorded, and who is involved in informing and making choices. Documentary analysis could have been particularly useful as a means of identifying themes and topics to be pursued in more depth in interviews with the participants involved in transition planning meetings. The content of the documents and the way they are produced (i.e. who writes them, who verifies the content, what participants feel was said but not recorded, etc.) could be used to structure discussions with practitioners, family members, and disabled young people.

Thirdly, *focus groups* have been promoted as an efficient and empowering approach in disability research. Focus groups are sometimes referred to as focused group interviews as the researcher decides on the membership of the group, usually based on the members sharing certain characteristics of relevance to the study, and facilitates the discussion on a pre-selected topic. Focus groups are particularly useful when the researcher wants to explore people's experiences, opinions and feelings (McLaughlin, 2012). They are often used at an early stage of research to discover general viewpoints which can be used to inform the design of larger studies (Smithson, 2008), but can also be used in mixed method research with disabled people to explore or clarify the context of quantitative findings (Kroll *et al*, 2007). Focus groups are particularly useful for exploratory research that addresses broad questions about 'why', 'how', 'when', 'where', and 'what kind' (Stewart *et al*, 2009).

Participant observation, documentary analysis, and focus groups are all valid approaches that could have been deployed within a realistic evaluation framework but pragmatically and ethically these methods posed additional challenges for the researcher in terms of time, cost, informed consent, and confidentiality that could not be justified in terms of the overall research strategy.

Data analysis strategy

Analysis is the interplay between the researcher and the data.

(Strauss & Corbin, 1998, p.13)

- **Secondary analysis**

In considering which methodology to apply to the analysis of the secondary data, I was aware that the interview transcripts, as documents, could be analysed using a number of approaches including grounded theory, critical discourse analysis, interpretative phenomenological analysis, and narrative analysis. However, the interview transcripts did not employ the detailed transcription notations (e.g. Jeffersonian transcription system) that would enable approaches that relied on detailed transcription of every word, utterance, and silence.

One should be cautious of treating transcripts as 'true' representations of speech. Despite technical guidelines transcription remains an imperfect process of constructing a textual version of the original interaction (Nikander, 2008).

Transcripts are constructions and as such are products shaped by the researcher's theories (Skukaskaite, 2012). A symbolic interactionist approach stipulates that the researcher must enter the everyday world of study participants to appreciate their experience (Milliken & Schreiber, 2012). Critical realists argue that there is a material dimension to people's lives that is separate from language, and that language which describes our social realities is constrained by material conditions.

Sims-Schouten, et al (2007) state that while the interviewees discourse can help to illuminate the constraints of the 'real world', the researcher needs to explore material concerns outside the boundary of the interview by means of a literature review, and by exploring the local social and physical environment in which the respondent lives. However, there are critics of this approach who claim that a reflexive approach would recognise how the researcher is helping to socially construct the interview, and how a skilled analysis of the interview will reveal in the discourse, patterns relating to social and political structures (Speer, 2007).

The secondary analysis of the Timescapes data archive (*Choice & Change Project*) qualitative longitudinal dataset was carried out using *thematic analysis* based on the work of Attride-Stirling (2001). A thematic network analysis consists of three broad stages: (a) the reduction or breakdown of the text; (b) the exploration of the text; and (c) the interpretation of the exploration. These stages can be understood in six steps (Box 1).

Box 1: Stages and steps in thematic network analysis

Stage A: Reduction of Text

Step 1: Code material

Step 2: Identify themes

Step 3: Construct thematic networks

Stage B: Exploration of Text

Step 4: Describe and explore thematic networks

Step 5: Summarise thematic networks

Stage C: Integration of Exploration

Step 6: Interpret patterns

Source: Attride-Stirling (2001)

Thematic analysis involves a search for patterns of categories that help to describe and interpret a phenomenon. While grounded theory follows an inductive approach in which theories emerge from the collected data, my own approach to the research design has taken a 'general inductive approach' in which data analysis is determined by both the research objectives (deductive) and multiple readings and interpretations of the interview data (inductive):

Data analysis is determined by both the research objectives (deductive) and multiple readings and interpretations of the raw data (inductive). Thus the findings are derived from both the research objectives outlined by the researcher(s) and findings arising directly from the analysis of the raw data.
(Thomas, 2003, p.3)

Step 1: code material: The interview transcripts from the secondary data were read fully. The texts of the transcripts were printed and blocks of text that appeared to have relevance to the research questions were highlighted using a highlighter pen. The highlighted texts were read again and salient statements representing relevant beliefs and processes were identified and given codes. For example the code 'experiential knowledge' included text segments such as "We had a walk round the school and...looked and I, doubted the toilet" (mother of disabled young man moving

schools). Texts were then dissected using the coding framework with manageable quotations and short segments of the interviews ‘cut and pasted’ from the word documents into a separate word document.

Step 2: identify themes: Once the text had been coded, more abstract themes were applied to the coded text segments. The aim was to reduce the data into a more manageable set of significant themes that concisely summarised the main issues. In this case 12 codes were grouped into 4 clusters and led to 9 themes being identified (table1).

Table 1: From codes to themes

Codes	Themes identified
<ul style="list-style-type: none"> - Emotional support - Trusted professionals 	<ol style="list-style-type: none"> 1. Emotional support from a mother supports informed choice 2. Trusted professionals seen as enablers of informed choice
<ul style="list-style-type: none"> - Parental beliefs in y.p abilities - Individual sense of empowerment 	<ol style="list-style-type: none"> 3. Parents’ attitudes towards young person’s abilities influences involvement in choices 4. Young person’s sense of agency contributes to involvement in choices.
<ul style="list-style-type: none"> - Experience - Information format - Practical help with choices 	<ol style="list-style-type: none"> 5. Practical experience relevant to choices is informative 6. Information in accessible format supports choices
<ul style="list-style-type: none"> - Information overload - Inaccurate information - Conflicting information 	<ol style="list-style-type: none"> 7. Right amount of information 8. Accuracy of information 9. Consistency of information

Step 3: constructing the networks: The 9 Basic Themes identified in table 1 were arranged into 4 groups based on conceptual correspondence and these were interpreted as Organising Themes. Global Themes unifying the organising themes were then produced (table 2).

Table 2: From Basic to Organising to Global Themes

Basic Themes	Organising Themes	Global Themes
1. Emotional support from a mother supports informed choice 2. Trusted professionals seen as enablers of informed choice	Emotional support from trusted other(s)	Empowerment and support
3. Parents' attitudes towards young person's abilities influences involvement in choices 4. Young person's sense of agency contributes to involvement in choices	Agency (empowerment)	
5. Practical experience relevant to choices is informative 6. Information in	Meaningful information	Information content, accessibility and trustworthiness

accessible format supports choices		
7. Right amount of information 8. Accurate information 9. Consistent information	Correct information	

Step 4: describe and explore the thematic network: The Global Theme of *information content, accessibility and trustworthiness* will be used to demonstrate this step (figure 1). This constitutes one thematic network comprising two Organising themes and 5 Basic Themes and explores the content of information and the ways in which it is made available to disabled young people and their parents.

The interview transcripts of the secondary data revealed the importance of disabled young people and parents having direct experience of a service in informing choice as evidenced by a disabled young woman being asked about the helpfulness of having information, who repeatedly uses the phrase “*going through it*”:

You could have a whole book on it, but it’s still unknown to you, because until you are there going through it, you don’t know.

The Organising Themes in the network suggest that disabled young people and their parents benefit from information that is meaningful to them and correct. A lack of trust in the information provided by professionals is a barrier to informed choice. The following is a quote from a mother giving her perception of the information provided by social workers:

I do think me husband will tell you, if he was sat here now he would say that it’s a bit, he will say it’s scary because ... they were giving us sometimes the wrong information, time and time and time again.

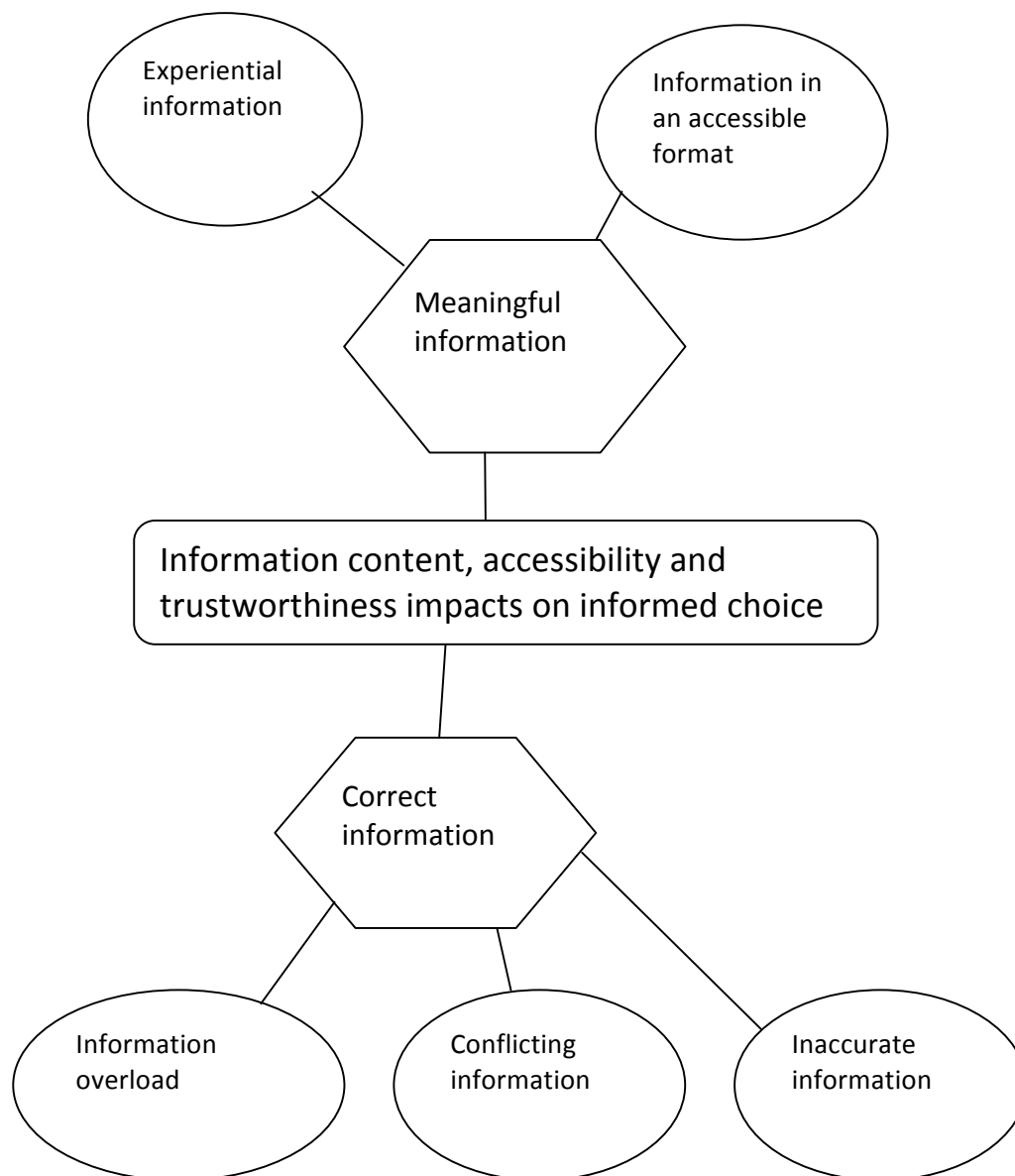


Figure 1: Thematic network for information format and style

Step 5: summarise the thematic network: The thematic network revealed two distinct components of informed choice: the role of others in terms of trust and emotional support, and how the actual information was presented/made available to disabled young people and their parents. It was not sufficient that the information was in an accessible format, disabled young people also needed to trust the source of the information and receive emotional support from a family member (generally mothers) in a way that empowered their involvement in choice-making.

Step 6: interpret patterns:

In step 6, the researcher must relate the principal themes and patterns that emerged in the analysis to the original questions; and propose some explication of the questions grounded on the content and exploration of the texts, and on the theoretical constructs guiding the research. (Attride-Stirling, 2001, p. 402)

The theoretical constructs of social capital and bounded agency (Evans et al, 2001) can be used to inform the analysis of the other Global Theme (*empowerment and support*). Analysis of the text provides evidence to support the hypothesis that a disabled young person's sense of individual agency (power to make decisions) and social capital (trust in parents, professionals, and others) have an impact on informed choice and involvement in choice-making. The following transcript extracts reveal significant differences in feelings of self-empowerment and support from others. In the first example a disabled young woman explains that although she may seek information and emotional support from others, important life decisions are made by her alone:

[Local Hospice] is good for the information and mum's good with the support, but at the end of the day it's my life isn't it?

In the second case, the parents of a disabled young man are asked if they feel their son has the right level of involvement in decisions regarding his care needs:

[Mother]: I mean it's funny because if the doctor comes here, or any professional comes here, [Young Person] will say "I'll go in me room where you can talk." So he sort of knows but he doesn't, he's, it's funny really when he says that cos you think well what's going through his mind, thinking well they're talking about me.

[Father]: But we have a saying like "Eh, it's adults now."

It should be recognised that interviews are themselves socially constructed contexts producing narratives that are context specific to the interview and may or may not

provide access to meanings relating to a wider 'reality' (Miller & Glassner, 2011). The interview should be regarded as a product of a situated interaction, rather than as the embodiment of the interviewee's pre-existing knowledge, beliefs and values. The research interview has been described as a social encounter whose meaning is negotiated between the participants, and Scott et al (2012) explore the 'dramaturgical complexity' of this relationship and how the interview can be shaped by the personality of the researcher.

Both Hammesley (2010) and Seale (2011) emphasise the distinction between data and evidence or, put another way, data collection and data analysis. Data is collected as a resource but in using or re-using data the researcher analyses and reconstitutes the data as evidence to support a theory or illuminate a research conclusion. Their central argument is that selection and interpretation of the 'raw' data is always involved, so there is no absolute distinction between primary and secondary data analysis.

- **Analysis of primary stakeholder interview data**

In phase two of the research strategy I adopted a looser, more fluid approach to data analysis than had been the case in phase 1. The emphasis in this phase was on discovering more specific hypotheses regarding context, mechanism and outcomes relating to the barriers and facilitators of informed choice for disabled young people. Disaggregating the data into small chunks for coding purposes may distort meaning by removing extracts of speech from the original context and selective quotations from interviews can therefore be biased or misleading (Taylor, 2012). By attentive listening to the interview audio recordings and re-reading the typed transcripts (see appendix 2 for an example of a transcript) I identified 'folk theories' and 'folk wisdom' of the stakeholders that could be used to develop more specific hypotheses of 'what works for whom, in what circumstances'.

Ethical issues

The fundamental principle in ethics is that no one should be harmed by research. Who has the authority to make this judgement: should the researcher act as 'judge and jury'? (Robson, 1993). This is rarely the case nowadays as most research has to satisfy the requirements of some ethical body. In the case of this dissertation,

approval was gained from the faculty ethics committee prior to any contact with participants.

The application provided details of the practical means by which the issues of informed consent, non-harm, and confidentiality would be addressed. Information sheets providing details of the researcher and the research project were given to all participants (appendix 1). Interview subjects received further verbal information immediately prior to the interview and were asked to sign consent forms regarding their participation. All participants gave their written consent for interviews to be audio-recorded.

In addition to the process of the research the author reflected on the interpersonal relationships involved in the interaction with participants and maintained an awareness of the question of power and having a relationship with all participants based on trust, respect and reciprocity (Barton, 2005). Social science is not 'value-free' (Padgett, 1998).

3. Findings

- **Secondary analysis**

Some of the cohort of disabled young people in the secondary data had cognitive and communication difficulties. The challenges for the researcher in conducting a meaningful interview, without using leading questions, and the challenges in analysing interview transcripts, were evident in the following extract from an interview with a 16 year old young man, when asked how he perceives his parents' views on the choice of a new school:

“WM [interviewer]: And do you think, did mum and dad think it would be good to go to that school?

YP [young person] : Yeah.

WM: Why did they think it would be good?

YP: No .. yeah.

WM: Why does mum think...?

YP: No it isn't good.

WM: It's not good?

YP: No.”

While retaining an awareness of the challenges of analysing interview transcripts where some of the participants had cognitive and communication difficulties, overall there was a rich data set available which was used productively to address the first two research questions and to signpost areas for further exploration in the primary interviews with stakeholders.

What information and assistance is available to disabled young people in making choices?

Information in an accessible format at the right time is regarded as a prerequisite for informed choice (Maddison & Beresford, 2012). However, the research subjects were not always convinced that all information was necessarily helpful:

I think it's unhelpful sometimes cos everybody just freaks you out a bit. It's a bit too real when you have the information, whereas when you're just going

through it, it's probably a good thing to think and what can you say, and nine times out of ten it's always right anyway. (Young Person: secondary data)

There were other disabled young people who did find information useful and the internet a helpful resource:

WM [interviewer]: Having information, perhaps written information or Internet information or watching DVDs or videos about what you're going to do?

YP [young person]: Internet.

WM: Having Internet information?

YP: Yeah.

M: About your leisure activities?

YP: Yeah.

Although the internet was regarded as a useful resource by a few of the young people, the most common strategy for gaining information to inform choice was experiential, such as the young person visiting a resource (e.g. a new school or hospice). For those young people with the most severe cognitive and communication difficulties, choices were limited to routine aspects of daily living and were usually achieved by being presented visually with two choices (e.g. a carer holding up a choice of two articles of clothing):

WM [interviewer]: Do you like them to hold things up and show you and to talk to you? Is that how you like choice?

CF [paid carer supporting young person]: We do that when we go shopping, don't we [young man, 21 years]? If we go out anywhere, if we're looking at anything for [name] ... We hold things up for you, don't we [name]?

Who is involved in assisting disabled young people with informed choice?

Analysis of the secondary interview transcripts revealed that parents, and especially mothers, play the most significant role in supporting disabled young people in making choices by listening, providing emotional support and sharing in the decision-making process. The extent to, and strategies by which, parents actually informed

choice varied considerably and were seen to be related to cognitive ability and age of the young person.

One of the main findings from the Choice and Change project was that the process of making significant choices was shared between the young people and parents, and this was welcomed by both parties (Mitchell et al, 2011). However, the secondary analysis of the subset of the data found that parents often had a more nuanced approach to deciding which choices and to what level the young person should be involved, as evidenced by the parents in the following extract who think they know their child's views on his Personal Assistant without consulting him, but were prepared to take him to visit his new school:

[Interviewer]: *So has [young person] been involved in, in again this process of sorting out [female PA's] move?*

F [Father]: *No...*

M [mother]: *No...*

F: *...no, not, that's .. he, he's aware .. he'll be aware of it, we haven't hidden that from him...*

M: *No.*

F: *...but .. if you asked him who would you like...*

M: *He'd say Mrs [surname].*

F: *...I would, I would think he would say [female TA first name].*

M: *Yeah. No we haven't worried him with that, cos then he'd start to panic. But he's looking forward to going to look round the school.*

Interviews with a 21 year old woman present a picture of someone who uses her mother for emotional support, rather than information and advice, and she is critical of the role of many other parents with disabled children in decision-making:

WM [interviewer]: *Do you think some young people do rely on others then too much?*

YPF [young person]: *Yeah. I think as soon as, with some parents, because they just hear the word disability or like an illness, they wrap them up and they make all the choices and they put them in this like lovely fluffy world, do you*

know what I mean? Lovely pink fluffy world, or blue (laughs) if you're a boy I suppose, and everything's perfect and you know what life is not like that, and I think people should know more about life so they can experience it.

The role of professionals (doctors, nurses, social workers, etc.) was rarely acknowledged in the secondary data, or where it was mentioned, often portrayed in a negative way. There were some exceptions to this generality, especially in the few cases where the young person had established a long and trusted relationship with a third sector service provider such as a children's hospice. Evidence of professional input to informing choice from the secondary data set was largely either absent, or seen as being inconsistent, coercive, and sometimes inaccurate by those interviewed:

YP [young person]: Yeah, like one [doctor] will say one thing and another [doctor] will say another, which is a big massive thing.

[Interviewer]: Mm, mm. How does that make you feel?

YP: I don't know I just, it just sort of pisses you off in a way, don't it really, when one, cos they're meant to be the ones who like know it all and they haven't got the answers. Well why do I even bother then, do you know what I mean?

The secondary analysis introduced the first phase of the realist evaluation cycle by identifying middle-range theories that point to the potential mechanisms and contexts that may lead to certain outcomes. These theories indicated the importance of emotional support (especially from mothers); involvement in choice being related to the individual's cognitive and communication abilities; professionals being largely peripheral to informed choice; and the importance of accessible and trustworthy information, especially experiential, in informing choice.

The knowledge gained from the secondary analysis informed the second phase of the research strategy: interviews with a range of stakeholders in order to develop specific hypotheses in terms of what might work for whom in what circumstances with a focus on the facilitators and barriers to informed choice in the context of self-directed support for disabled young people in transition.

- **Primary data analysis: hypotheses development using stakeholders' knowledge**

The realistic explanation of programs involves an understanding of their mechanisms, contexts and outcomes, and so requires asking questions about the reasoning and resources of those involved in the initiative, the social and cultural conditions necessary to sustain change, and the extent to which one behavioural regularity is exchanged for another.

(Pawson & Tilley, 1997, p. 154)

Pawson & Tilley (1997) describe the distinctive knowledge of *subjects*, *practitioners*, *evaluators*, and *policy makers*. *Subjects* are most aware of the mechanisms in operation; the reasons and resources which encourage change. *Practitioners* translate policy into practice and will have direct experience of what it is about the policy that works (mechanisms), to have experienced successes and failures (outcomes), and to have some awareness of the people and places for whom the policy works (context). *Evaluators* tend to carry theories into their contact with subjects and practitioners and will begin to develop context, mechanism, and outcome (CMO) configurations, but may lack local detail. *Policy makers* will hold overarching theories about how the initiative will generate positive benefits (outcomes).

The policy of self-directed support is intended to improve outcomes for all adults and children who require social care supports. The guide to the *Social Care (Self-directed Support) (Scotland) Act 2013* makes clear the expectation of behavioural change from both local councils in terms of listening to what people want, empowering them to achieve positive outcomes, and for individuals to think and act differently about their support needs by accepting both rights and responsibilities (Scottish Government, 2013).

This need for behavioural change from local authorities and individuals was emphasised in the interview with the Government policy maker:

The way that care and support has been provided in the past and the lack of information about things they could do, not just for the individual but for the social worker themselves has meant that people have made, not rash decisions, but decisions that have been automated, so they will pick from this list of services kind of thing, so there is something about informed choice of there being that wide range of different options and things you can do in a different way if you are given the right information.

Pawson & Tilley (1997) point out that a vast web of unarticulated theory lies behind any policy or social intervention, but these theories generally remain implicit or are presented as broad assumptions; for example that choice and control in SDS will lead to improved outcomes. How the policy of self-directed support is expected to lead to behavioural change and improved outcomes for individuals requiring social care support can be thought of in realistic evaluation terms of context (C), mechanism (M), and outcomes (O) configurations as:

Variety of providers of good quality support (C) + Informed choice and control for the individual (M) = Improved well-being for individuals and their carers (O).

The potential for self-directed support to transform the lives of disabled young people and ease the transitions process was stated by the Co-ordinator of a national transitions forum (a third sector organisation):

The potential of self-directed support as it applies to young people with support needs in transition...that is the place where we should be making it work...it is easier to work where people are not caught up with existing services. My expectation is that young people and families will more readily adopt self-directed support models than say people in families who may already be engaged in traditional service provision, day centre provision for example for some years.

Researchers should be CMO configuration experts and the test of validity for a realist investigation is not the true representation of the participant's attitudes or beliefs, but whether the data accurately captures those aspects of the subject's understanding which are relevant to the researcher's theory:

On the realist model, data collection is thus charged – not with the descriptively infinite task of capturing the stakeholder’s ideas, beliefs, hopes, aspirations about a program, but with the task of demonstrating which aspects of these beliefs are relevant to the CMO theory under test, so that the respondent can contribute to that test. (Pawson & Tilley, 1997, p.164)

Facilitators of informed choice

- **Support**

Support (both emotional and practical) for disabled young people was seen as an essential component of informed choice and it was recognised by a number of stakeholders that this support could come from a variety of people, and that the disabled young person needs the space and time to accept the support on their own terms as indicated by the statements from the policy maker and the Head of a college:

I think this [support for the individual in terms of informed choice] is the crucial part of making care and support work for people and that is something that we are exploring quite a lot policy wise and I know that people at the front-line explore it all the time in terms of your information and support can come from a variety of places [...]. (Policy Maker)

What made that possible? She was not forced into it. She had enough time to work things out in her own mind. (Head of Independent College)

A disabled young woman indicated the importance of the availability of advice and support from trusted others but stressed that she was the one who had chosen these people and the final decision was hers to take:

When I am really unsure about something I will ask people. I surround myself with people who know me. I am going to make the decision, but ‘help!’ [...]. At the end of the day, I will make the call. But if you can get other people’s

views, their take on it, to see where they come from, because they may be able to see aspects that I may not have thought of. (Disabled Young Person)

Support from peers can also be a significant factor in informed choice:

What people tell us is the most helpful is when someone in a similar situation tells them what has happened to them. It is hearing from each other. I strongly believe that is the way that it will work. (Co-ordinator, National Transitions Forum)

- **Advocacy**

Having someone prepared to negotiate on behalf of the young person was seen as essential if informed choice were to be realised.

For one young person self-directed support has worked brilliantly for her because her parent is so confident and capable and able to negotiate, and a lot of carers don't have those skills. (Carers' Advocate)

An alternative approach to advocacy was that of self-advocacy where an organisation supported a group of young people with learning disabilities to advocate for themselves.

Our experience is in that working with young people individually and collectively on SDS as an idea in [name of Scottish Government test site region] before SDS had started seemed like a very good way to do it because there wasn't then...it wasn't loaded with anything else...it wasn't loaded with the closure of your day centre. [...] Many of that group when SDS became an option for them chose it and it has worked well for them. (Co-ordinator, National Transitions Forum)

- **SDS and family networks in rural areas**

Urban Region in partnership with the Scottish Government piloted self-directed support for disabled young people in transition. A Care Inspectorate scrutiny report

found that all participants they interviewed were positive about SDS, with the emphasis on choice and control leading to improved quality of life. However, parents were often critical of their experience of transitions and believed that SDS could be better promoted by social work staff (Care Inspectorate, 2011).

The introduction of self-directed support, with the young person being given an individual budget, was seen as being a facilitator of informed choice in rural areas where there were strong family networks to call upon and SDS can also be used to finance micro-enterprise (Lockwood, 2013).

There are a few examples of people in rural areas thinking of innovative solutions such as social enterprises but there are lots of areas where there really is nothing for the young people to do, but I see SDS as the solution to that. (Independent Consultant)

In a rural setting perhaps the young person grew up there, has a good family network, good friends, and finds it really easy to recruit a staff of ten who can step in for each other and work appropriately [...]. (Carers' Advocate)

- **Positive expectations**

Positive expectations whether from parents or professionals with a focus on strengths and achieving positive outcomes can contribute to informed choice.

If you start from someone's own interests and aptitudes you're much more likely to move better and achieve better outcomes, whether that is meaningful things to do, whether its social skills. [...] Just knowing you have a choice can lead to positive outcomes because suddenly they have got control, suddenly the responsibility is not with somebody else, you have some control over those outcomes. (Independent Consultant)

It was recognised that many parents and professionals would benefit from support and possibly training for them to adopt an outcomes focus based on a strengths' model that accommodates positive risk taking.

Awareness and training for parents and advocates so that they have the information. You need local stories that you can relate to. (Social Worker)

There is risk; other people get to take risks. Informed choice must include the right to take risks and that is the thing that people don't get. (Independent Consultant)

- **Experiential knowledge**

As with the participants in the secondary data set, there was evidence from the interviews of the importance of experiencing a support or a service first-hand rather than relying on written or other second-hand information.

I suppose if you wanted to, if you want someone to assist you, you can go onto Google and get the people from there to help you that way. I am a very old school person. If I want to go and see something I will see it. I like people, don't get me wrong, but I would rather go and see it. (Disabled Young Person)

Barriers to informed choice

Stakeholder interviews revealed a number of barriers to genuine informed choice for disabled young people including a lack of a variety of supports especially in rural areas, insufficient accessible information, low expectations for the disabled young person from parents and professionals, the individual young person's cognitive and communication difficulties, organisational bureaucracy, and services that were not working collaboratively.

- **Lack of accessible information**

Disabled young people and their families need accurate and trustworthy information in a format that meets their needs. While awareness of this requirement is increasing there is a need for this to be more consistently realised in a way that disabled young people value.

There is a lot still to be done by provider organisations about the information they provide to support choice and how support organisations market themselves. I can't help feeling that there is a subtlety to it that hasn't been

picked up on yet. [...] I suspect it is going to be around personalities and organisational culture and attitudes and I think there is a long way to go. (Co-ordinator, National Transitions Forum)

- **Parental attitudes**

It was recognised that parents are often under severe stress at times of transition for their child and that can influence their ability to promote choice for the young person:

I am usually called upon when things are not going well and quite often the youngster has perhaps such a complex need that they cannot have a voice except through their parent carer and the parent carer is so worn and tired that they can't be imaginative in suggesting what might be best. They want services to identify different options, so there is some kind of menu of suggestions. (Carers' Advocate)

Professionals were sometimes critical of parental attitudes and expectations in terms of parents not allowing their adult child to engage more fully in decision-making and attempting to avoid risk:

What I am picking up, it's a classic social work issue, and also I suppose a policy issue, is parents letting go. (Policy maker)

I see families as a bit of a hindrance at times. As social workers we are trying to build independence and it is frightening [...] we are trying to give young people a voice but a lot of parents speak on their behalf [...]. (Social Worker)

One barrier for young people in transition in particular is, and, it's with the best will in the world, it is their parent/carers and some of it is that they are so used to making decisions for that young person [...]. (Independent Consultant)

However, there was recognition that parents often feel unsupported and lacking information at times of transition and this can understandably cause them to try to take some control in such stressful situations:

I think to criticise parents for that [not including the young person in significant choices] is not the right thing at all. [...] Who can criticise when the system fails so badly [to provide information and options]. They will say 'I will settle for the thing that gives most security'. [...] The use of self-directed support in that decision-making process through transition at an early age, you can look at young people taking control of their lives gradually and parents giving up control of things using the self-directed support model. (Co-ordinator, National Transitions Forum).

- **Professional attitudes**

Professionals can also express low expectations for disabled young people and to operate from a deficits, rather than strengths, perspective and for the professional to be seen as the problem-solver, not the individual:

Professionals working with young people see the not possible and not the possible. It doesn't fit in the box as we understand it therefore the answer is no. (Independent Consultant)

For me there is something about expectations that we have as professionals or carers, looking at someone and asking what we think someone could achieve and then only ever being pegged at that level. This can filter into the young person so that they think that is all they can do. [...] Generally there is a lower level of expectation for our young people and that acts as a barrier to informed choice. (Head of Independent College)

But if they can't figure it out, they can't work out how you can figure it out. Because they can't come up with solutions, then when you come up with solutions they go 'oh, where did that come from?' (Disabled Young Person)

In Urban Region, despite SDS being in place for the past 3 years, some services gave the impression that they were the ones who defined how realistic a young person's goals were, and did not promote informed choice as the norm, although acknowledging that 'potentially' young people could get access to information:

It's about supporting the young person to work towards their goals and ambitions. To work towards these obviously they have got to be realistic.
(Service Provider)

Potentially there are opportunities for them [young people] to meet with those that provide social care and find out more information about that service. [...]. There are some choices of where you want to live when you leave care and potentially opportunities to visit these places. (Service Provider)

What I don't think is helpful are visits to service providers [...] because it raises expectations [...]. (Social Work Manager)

- **Child and adult services not working collaboratively**

There are issues in Urban Region with the lack of integration and coordination of services both between child care and adult social care, and social care and health services. Health and social care integration has not resolved these issues, because child care services are led by the council, while the NHS leads on adult care services. This has created an organisational divide between child services and adult services which can cause problems for disabled young people at transition.

I get an impression that sometimes people can feel a bit overwhelmed by all the different professionals, repeating the same story again and again. It is that lack of integrated services are a barrier to informed choice because you are getting all the different parts of the sector coming in at different times with their different assumptions about how they can help you. (Policy maker)

There is not a clear pathway for people with learning disabilities. NHS and Social Work integration has not solved this. We are further away from children's services which remain with the Council. (Head of Independent College)

There are issues about engaging Adult Services in the transitions planning process. A lot of the planning for transitions is done by Children's Services on

their own. It isn't good [...] they are not necessarily the best people to be advising about choices for adulthood. (Social Work manager)

- **Bureaucracy**

Organisational bureaucracy with its understandable requirements for assessing against eligibility criteria, managing risk, and ensuring proper use is being made of public funds can be a barrier to informed choice, limiting responsiveness, flexibility and creativity:

It is not unusual for a school or a parent to want the young person to come here but they don't have a social worker, and if they don't have a social worker then they have to get one. (Head of Independent College)

[...] if you want to go out for an evening [...] then you should be allowed to do so. You are still obstructed by gatekeepers [from Social Work] who say actually you can't just do that; we have to make sure it's done properly. (Disabled Young Person)

- **Lack of services in rural areas**

The lack of existing social care supports in rural areas was raised by a number of stakeholders as being a barrier to choice and for those without strong family networks or local innovative social enterprise initiatives this can result in either a lack of choice or no supports whatever.

It is reflected in the national strategy because it did come up as an issue about the lack of providers in rural areas [...]. (Policy Maker)

Quite a number of self-directed support clients are SDS clients not through choice and the reason is there is no service provider in that area. (Social Worker)

As you go out of here [the city] there are limited resources in terms of supports that are around. You know, there are some places that there are not any

housing support hours or it's one person that is doing it. There are no housing options [...] and transport is a big issue [...]. (Service Provider)

Even where family networks or local social enterprises are available to provide supports, the options by which self-directed support is provided are restricted if there are no services available from the local authority or an established third sector care provider.

One of the fundamental issues in rural areas is over genuine choice [...]. More innovative approaches to providing choice such as through family networks or social enterprises are based on the assumption that people are going to choose option 1 [a direct payment]. [...]. So the danger is you can go down the family network or micro-enterprise approach but there would still be a reduction in choice [...]. (Co-ordinator, National Transitions Forum)

- **Status quo**

The default option is naturally perceived as the normal choice. Deviating from the normal choice is an act of commission, which requires more effortful deliberation, takes on more responsibility, and is more likely to evoke regret than doing nothing. These are powerful forces that may guide the decision of someone who is otherwise unsure of what to do. (Kahneman, 2011, p. 413)

For some young people there is a need for someone to advocate on their behalf in order to realise choice, and there is a possibility that making choices based on what their peers have chosen before them could promote the status quo at the expense of innovative, person-centred choices.

Some young people can identify that they want to come here but if they don't have a pushy parent or social worker then they may not be able to realise that choice. (Head of Independent College)

Young people tend to make choices based on what their peers have done. [...]. A lot of the young people will maybe know someone who has worked

with that service and will get information about them and that usually influences their decision about who they will work with. (Service Provider)

A further barrier to informed choice can be the individual's attitude towards the relationship between the individual and the state in terms of self-directed support and accepting the associated rights and responsibilities:

When you are faced with making decisions yourself when it goes wrong sometimes people can revert back to blaming social work as they can expect to be taken care of and so there is a kind of challenge there for individuals[...] it is a different model of social care. (Policy Maker)

- **Individual abilities**

The individual's communication and cognitive abilities were seen as factors that impact on opportunities for the young person to make informed choice on significant life events. However, it was recognised that choice making is a process and that these skills can be developed to some extent.

[...] people need to have some choosing ability and I think a lot of young disabled people don't because somebody may be only able to choose what clothes to put on, or because of their disability someone else makes these choices all the time, so I think informed choice means that you need to let people learn to choose. [...]. They need to get little choices at an earlier age, and they need to be allowed to choose the wrong thing (Independent Consultant)

There is a danger that insufficient support will be given to disabled young people with more complex needs in order that they may realise informed choice.

The reality is that [the individual's cognitive and communication abilities] is going to be an issue...no doubt about it...but there would be a danger if it became too much of an issue. We should know how to support people with complex needs to make choices. (Co-ordinator, National Transitions Forum)

4. Discussion

The purpose of this study was to explore the phenomenon of informed choice in relation to the policy of self-directed support for disabled young people in transition from child to adult social care supports and to develop theories and hypotheses in terms of context, mechanism and outcomes configurations that would suggest what works for whom, in which circumstances.

The first phase involved the secondary analysis of interviews with six disabled young people and their parents/carers. A thematic analysis approach identified concepts relating to middle-range theories relevant to the first two research questions: which people were involved in informed choice with disabled young people, and what information and support was available to these young people with regard to informed choice?

The findings from the secondary analysis suggested that a trusted confidant (mainly mothers) was an important emotional support for disabled young people in making choices. Involvement in choice appeared to be related to the young person's cognitive and communication abilities with less able individuals being limited to either/or choices related to basic daily living activities. Professionals from the young people and parent interviews, were in the main absent from informing choice or were seen as providing inaccurate or misleading information. However, there were a couple of examples where an individual had a long-standing relationship with a service provider and regarded the staff as trusted providers of information. Analysis of the secondary transcripts revealed the need for the right type of information at the right time for individuals, and the importance placed on visits to a service/resource and lived experience.

These middle range theories based on concepts identified from the thematic analysis of the secondary data informed the next phase of the research strategy which was to develop more specific hypotheses concerning the third research question: what are the facilitators and barriers to informed choice for disabled young people?

The second phase of the study involved semi-structured interviews with eight stakeholders representing the range of interested parties with this policy initiative in Scotland. These interviews followed a realistic evaluation approach to refine and further develop the middle-range theories from phase one in order to come up with more specific hypotheses about what works for whom, in which circumstances in order to explore the facilitators and barriers to informed choice for young disabled people in transition.

Table 1: CMO configurations that facilitate informed choice

Context	+	Mechanism	=	Outcome
Strong family networks in rural areas		Flexibility with SDS to use direct payment to employ family members		Some choice but mainly limited to SDS option 1
Variety of good quality support providers		Accessible information (right information at right time for individual)		Informed choice a reality
Professionals and parents provide supportive environment for the young person based on strengths		Self advocacy supports individual to articulate choice		Informed choice a reality

Table 1 provides examples of the contexts and mechanisms that can make informed choice a reality for disabled young people in transition. Informed choice requires not only accessible information but also individuals being able to express opinions within supportive social networks of parents and professionals.

Table 2: CMO configurations that are barriers to informed choice

Context	+	Mechanism	=	Outcome
Traditional menu of services		Information limited to existing services		Choice limited to existing services
Low expectations and risk averse culture among professionals and parents		Only choices available to individual are 'tried and tested' services		Choices limited to the status quo

Health & Social Care integration that does not include children's services: child and adult services do not work collaboratively	Information is service specific and not accessible to all disabled young people	Young people and families lack both adequate information at the right time, and continuity of professional support to make informed choices
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The mechanisms and contexts that get in the way of informed choice include low expectations of parents and professionals regarding young people's abilities, a bias towards the status quo of supports and services, and organisations that are characterised by bureaucracy and a lack of collaboration especially between child and adult services. The latter finding challenges preconceptions that health and social care integration will lead to a seamless service for the individual, if child and adult services remain organisationally apart and have not developed processes to ensure close collaboration at transitions. However, Mitchell (2012) found that SDS as a policy initiative has the potential to encourage innovation at an individual and organisational level that can result in organisations integrating around the disabled young person in transition.

All choices involve a logical and an emotional component. Informed choice requires not only accurate and accessible information, but also the emotional resources to make choices. The emerging theories and hypotheses point to the importance of disabled young people being supported over a period of time to make choices, and the vital role of family, peer and organisational networks that disabled young people can tap into for information and support. This suggests that social capital, in terms of family and wider community networks, may have a significant impact on informed choice. The theoretical concept of social capital could usefully be applied as a way of explaining the data and can be incorporated within a critical realist approach:

In social interventions the stakeholders' capacity for choice making is, of course, subject to social constraint and is always limited by the power and resources of their 'stakeholding'. (Pawson & Tilley, 1997, p. 216)

Consideration needs to be given to structural influences on choice, and the concept of 'bounded agency' (the interfusion of individual agency and the social environment) may be useful in understanding choice and control (Evans *et al*, 2001). A critical realist approach recognises that the individual's capacity for choice making is subject to social constraint and is limited by the power and resources of their 'stakeholding'.

Providing choice risks increasing inequalities for disadvantaged groups (Wilberforce *et al*, 2011). The potential for one social policy (self-directed support) to act to the detriment of another policy (reducing inequalities) is highlighted by Arksey & Glendinning (2007):

Thus people who have or can access resources such as wealth, knowledge and information, personal skills in dealing with professionals, or personal familiarity with decision-making professionals are likely to be advantaged when making choices and so secure better outcomes than those who are 'resource poor.' (p. 168)

While social capital can be ill-defined and difficult to quantify, there are implications for practice, policy and research for disabled young people in transition:

Service delivery to young people can be enhanced by taking into account the contributions social capital can make to their security and well-being, to the formation of their aspirations, and to the creation of opportunities for them to access information, education and employment. (Catts & Allan, 2012, p. 222)

The focus on the benefits of social capital ignores the unequal power held by those in the network, and there is a risk that too much bonding social capital has the potential to lead to conformity, restricting individual freedom. Malecki (2012) points to an 'innovative milieu' being more useful for creating change, whereas social capital is more about stabilizing relationships. Social capital seems to have two contradictory roles: the 'glue' that binds a network and the 'lubricant' that empowers network interaction.

The role of social capital as a mechanism impacting on outcomes from self-directed support could be enacted through informed choice. The literature on social capital tends to under emphasise the role of families in constructing social capital and deserves greater examination (Winter, 2000). Strong family networks in rural areas were seen as a solution to the lack of service providers in these localities, but there are dangers that strong bonding social capital in family networks that are deficit focused and risk averse with regard to disability could limit world views and restrict informed choice for disabled young people.

Methodological considerations

One of the strengths of realistic evaluation is that it focuses on generative mechanisms where causation is seen as acting internally as well as externally. This means that the goal of research is not just to study outcomes (effects) but attempts to explain why causal outcomes follow from mechanisms acting in contexts. Therefore social interventions work through the actions of mechanisms (the interplay of resources and reasoning) in a social context (social rules, norms, values and interrelationships).

Realistic evaluation is closely related to constructivist grounded theory although there remain significant ontological differences with realistic evaluation attempting to locate phenomena that exist independent of social actors. Realists, while accepting that social contexts differ, nevertheless search for causal regularities and have difficulties accepting the relativism of constructivists.

Realistic evaluation has been used in a variety of health and social research settings that are attempting to better understand how initiatives work. However, realistic evaluation has been criticised for neglecting the 'critical' element of critical realism and therefore abandoning the critique of power and injustice in favour of technocratic managerialism (Porter & O'Halloran, 2011). My own background as a social work manager perhaps leads me to be more comfortable with such an approach rather than with constructivism or 'pure' critical realism.

Combining secondary and primary analysis of qualitative data has proven to be a useful approach in terms of exploring the phenomenon of informed choice with a wide range of research subjects. Secondary data was used to discover middle-range theoretical concepts that informed the second phase of the study in terms of the interviews with a range of stakeholders to begin to develop and refine more specific hypotheses regarding contexts, mechanisms and outcomes (i.e. what works for whom in what circumstances?).

My approach to the study is best characterised as explorative rather than inductive and involved both inductive and deductive elements in the overall study. Thematic analysis was found to be helpful, especially in the analysis of the secondary data, but a looser approach to coding took place with the primary interview transcripts where the objective was to discover hypotheses based on stakeholder knowledge. Thematic analysis involves searching across a data set to find patterns of meaning. Whilst this is a useful approach to developing broader theories there is a danger that the individual narrative is lost and it is not possible to retain a sense of continuity and contradiction through any one individual account (Braun & Clarke, 2006).

Realistic evaluation encourages a 'teacher-learner' approach to the realistic interview, where the researcher clearly lays out emerging theories to participants and seeks refinement and new theories from stakeholders. In this approach both researcher and participant are in turn both teachers and learners. This differs from the approach taken by inclusive research with disabled people for example, where the person with the disability is seen to be the 'expert by experience' and the researcher a facilitator and recorder of the participant's lived experience.

The teacher-learner function was used in this study to an extent with all participants by sharing emerging theories from the literature and earlier interviews, and to see if these theories were supported, refined or rejected by interviewees. Throughout each interview I learned from the participant's knowledge and experience, whilst at the same time teaching (sharing knowledge and ideas).

Conclusions: implications for policy and practice

As the policy of self-directed support becomes widely implemented, disabled young people and their families will require assistance to make the underpinning principle of informed choice a reality. The policy of self-directed support is attempting to shift the balance of power away from state organisations towards the individual, to increase their ability to control and choose how their support needs are met. This qualitative study has explored the phenomenon of informed choice and has begun to develop broad hypotheses ('folk' theories) based on the accounts ('folk wisdom') of stakeholders.

Facilitators to disabled young people having informed choice were found to be related to the following factors:

- Supportive networks of family and professionals
- Advocacy
- Information that was accessible and accurate
- Experiential knowledge

Barriers to informed choice were seen to be related to:

- Parents and professionals having low expectations for disabled young people
- Capacity of the individual to make decisions and their communication skills
- Lack of integration/collaboration between child and adult services
- Organisational bureaucracy and risk averse culture

The limitations of the study are that the secondary data came from interviews conducted in England between 2008 and 2011. Scotland has taken a different policy direction to England on self-directed support with less emphasis on the individual budget aspect of SDS. Interviews with the service professionals and service user stakeholders took place in one Scottish region and may not be representative of other regions. Stakeholder interviews included only eight participants from a range of backgrounds and the views of these individuals may not be representative of a wider population. The sample for the primary interviews did not include any parents

of disabled young people although a carers' advocacy worker was interviewed in the stakeholder phase and the views of parents were represented in the secondary data set.

This study has explored the phenomenon of informed choice in the context of SDS and has begun to develop theories on the facilitators and barriers to informed choice. This will help to inform emerging policy and practice as SDS is implemented nationally in Scotland. The importance of supportive family and professional networks in helping disabled young people in transition become empowered to realise informed choice points to the importance of future research on the role of social capital on this issue. This study has highlighted the challenges of realising informed choice in rural areas and has found that while the role of micro-enterprises and the flexibility to employ family members can mitigate the lack of choice, there are issues remaining for those individuals who would prefer to choose the local authority to provide or arrange their support.

The policy of self-directed support is likely to be fully introduced in Scotland in 2014. There are significant challenges for local authorities, service provider agencies and others in ensuring that disabled young people and their families will have access to adequate assistance to make informed choice a reality. This study will contribute to the knowledge base emerging on self-directed support and personalisation to guide national policy and local practice. The findings from this study point to the need to involve disabled young people, their parents and formal carers/professionals at an early stage in choice-making, and to foster self-advocacy skills and supportive and innovative networks over a period of time. Informed choice needs to be seen as a process over time involving informational and emotional elements, rather than a series of one-off discrete events based purely on logical reasoning.

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Appendix 1: Participant information sheet and consent form

Participant Information Sheet

Name of department: Humanities & Social Sciences

Title of the study: Exploring informed choice for disabled young people in transition.

Introduction

My name is Fraser Mitchell and I am a post-graduate student at the University of Strathclyde studying for an MSc in Applied Social Research.

What is the purpose of this investigation?

I am interested in how disabled young people are informed about choices for services that support their social care needs at a time in their lives as they progress from school to adulthood.

Self-Directed Support (SDS) is seen as a way to increase choice and control for those requiring support to help them live independently. The Scottish Government has recently passed the *Social Care (Self-directed Support) (Scotland) Act 2013* to enable local authorities to make provision about the way social care services are provided. One of the principles of the Act is 'informed choice' when choosing an option for self-directed support. The aim of the research is to find out more about informed choice for disabled young people.

Do you have to take part?

Participation is voluntary and consent can be withdrawn at any time without providing a reason.

What will you do in the project?

I will be carrying out interviews in the Inverness area on the 25th and 26th June 2013 and will contact you, with your agreement, to agree a date/time/location for interview that is suitable to you. I will want to audio-record the interview (with your permission) using a digital recorder, and download the recording to a PC and later write down on a 'word' document what is said at the interview.

Why have you been invited to take part?

I am interested in interviewing a range of people who have first-hand experience of informed choice for disabled young adults in transition. Natalie Thomson, Social Worker, Self-directed Support Team, Highland Health and Social Care Partnership has suggested that you may wish to be included in the study.

What are the potential risks to you in taking part?

No specific risks have been identified for participants in these interviews.

What happens to the information in the project?

Interview transcriptions will be anonymised (names will be changed) and kept in a secure, locked place, and/or on a password protected PC. I will not use participant's names in the dissertation, or name the region where you live/study, but I would like to use some quotes of what you say. I will ensure that individuals cannot be identified in any subsequent academic paper or research publication.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

What happens next?

With your agreement I will arrange to meet at a time and location suitable to you. We will go through this information leaflet and you will be given the opportunity to ask any questions about the research and about your own participation. You can choose not to participate without giving a reason at any time.

If you would then like to take part in the study you should provide your written consent by signing the attached consent form. Please return this sheet to myself either by e-mail attachment or by post (contact details below).

Researcher Contact Details:

E-mail: Fraser.Mitchell.100@strath.ac.uk

Address: Fraser Mitchell, Flass Cottage, Crosshill Terrace, WORMIT, Fife, DD6 8PT
Tel.: 07515289627

Chief Investigator Details:

Dr. Alastair Wilson, Senior Research Fellow, University of Strathclyde

e-mail: al.wilson@strath.ac.uk

tel.: 0141 444 8108

This investigation was granted ethical approval by the University of Strathclyde ethics committee.

If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee

Research & Knowledge Exchange Services

University of Strathclyde

Graham Hills Building

50 George Street

Glasgow

G1 1QE

Telephone: 0141 548 3707

Email: ethics@strath.ac.uk

Consent Form

Name of department: Humanities & Social Sciences

Title of the study: Exploring informed choice for disabled young people in transition.

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences.
- I understand that I can withdraw my data from the study at any time.
- I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project.
- I consent to being audio recorded as part of the project: Yes/ No

(PRINT NAME)	Hereby agree to take part in the above project
Signature of Participant:	Date

Appendix 2: Interview transcript with young disabled person

Interviewee: YP (young woman with cerebral palsy, lives in own tenancy with social care support, wheelchair user)

Interviewer: FM

Date of interview: 25/06/13

Length of interview: 45 mins. (recorded time)

Location: Theatre cafe

Notes: General introductory greetings, explanations about the research study and informed consent were not audio recorded. Background noise impacted on the recording quality and at times made some speech inaudible. These breaks in the recording are indicated in the transcript.

FM: We discussed a little bit about yourself, where you live and some of the work you are involved in and some of your experiences as well...mm... Can you tell me about, you told me about the services that you do receive on a daily basis? How did, did you have a choice on services that you receive, or the support you need. Did you have a choice in that?

YP: I do now...it wasn't always such that way. I think that for a while it was just assumed that I would have the service because everyone else had it; that's the way the system was, and being a young woman you had to run within the system's realms. However, I am slightly different in a lot of ways in that a) I can't run and b) I don't do systemic behaviour. I am a unique individual with a unique set of needs and expectations. When self-directed support came along I went to a workshop because I thought it might be a good idea and I am like the more the person was talking, the more I am going 'is this for real?' Can I actually, is this actually going to work? And it does work, it really does work. Mmm, but it needs to work more. It is not enough...do you understand what I mean by that?

FM: Well, say a bit more. Is it not enough for you, or not enough for other people?

YP: It's not enough for the fact that...I know it's in its infancy here...and I completely respect that and I have the utmost respect for the people trying to get this off the ground. I understand that every new initiative has small but significant teething problems...mm..but different regions have been able to get it off the mark much easier and much quicker and I can't understand why the participation in such a project isn't higher on the uptake. I understand some reasoning for it but not all, because this is like your ticket to freedom. The way I understand it is...the way I understand how it works is that you have a support/care budget, whatever they like to call it...whatever the terminology is these days...and providing you don't use it to buy illegal services or illicit substances then...I am sure by that you understand what

I mean (FM: yes, yes)...then anything you do with self-directed support funds is supposed to enhance your life, but I have great difficulty with it. Although I have been able to achieve at some level which is great, I am still not able to utilise it to its full potential.

FM: Ok, explain a little bit more about that then.

YP: Because it is not widely known and agencies are not together enough to work with you.

FM: Ah, OK. And the people you have chosen to support you, are they from an agency or are they individually...?

YP: They are from an agency, and the reason why I have chosen an agency and not to employ individual workers is purely from a, my own security point of view. Because if you have an agency you are not responsible for finding any gaps in the support that is needed. If you take on individuals then you become the employer. Although that sounds great in practice, in theory rather, it is not so good in practice because you take a lot of unnecessary pressure on you. If people want to go down that route that's more power to them (laughs).

FM: I understand. For you at the moment the agency gives you some security and protection...less pressure, yeh?

YP: Because I've got my life to lead I don't need to worry about managing people. (FM: No, exactly, no). And that is what you become, you become a manager. A manager of people with all the sick pay, taking the initial staff on, so I am supported by an agency.

FM: And how, and how long has that been going on for?

YP: On the direct payments scheme, on self-directed support as it is now, three years. That is the portion of my support that is completely self-directed. The other portion of my care is, I don't know why, but it's not. So one part of my support is fine. The other part is OK in a way but it should be better.

FM: In what way should it be better?

YP: Just that the cross-over, what you have, if you want to go out for an evening, as long as you can prove that it is going to enhance your life and your welfare and your wellbeing, or whatever, then you should be allowed to do so. You are still obstructed by gatekeepers who say actually you can't just do that; we have to make sure it's done properly.... I am an adult.

FM: Where are the gatekeepers from? Are they from the agency or are they from social work?

YP: From social work.

FM: Can you sort of think back to about 3 years ago. How did self-directed support come about? Did someone come to you, or did you hear about it first?

YP: No, I had been going on and on about wanting to live my own life. [Background noise obscures 10 seconds of recording]. You can't do that...you have to run it by someone first, and it has to go before this board and that board, and suddenly I heard of this new thing that was happening that I might be interested in. That's when I went to meetings that were held...there were a series of workshops held. I couldn't believe what I heard...and I knew that is what I wanted. And then I slammed up against a brick wall..."Ooh, we are not up to speed on that yet", and I went "so I can't have this" and they said "no, not yet because we are not up to speed, we don't know enough". And then there was a change of management and there was one lady who said "we are trying to promote this self-directed support, would you be interested; this is how it works, blah de blah..." And then I was given my budget and I was told how it works... [few words indistinct]. That covers the support side but the social side is not working. (FM: OK) So if I want to, say I wanted to go to a conference in London or whatever and I wanted someone to go with me. I could use some of my SDS money to pay for someone to go. [few words indistinct]. But they say can I do this? And I say hey it's my own money, I can use it for what I want.

FM: So is there a lack of understanding among the staff; a lack of willingness, or just a fear that they are working in a bureaucracy where they have to check things out?

YP: It's all of these things. I think it's they are so used to working within an institutionalised ideology that they have to check with the gatekeepers every time. And I say "wait a minute I actually have a budget", and I can prove that I am using it for legitimate purposes, doesn't matter what it is just as long as it is nothing illegal or illicit and I have enough of the budget to pay for my ongoing support... I am probably talking too much.

FM: You are not talking too much at all. Just in terms of you taking that decision to take on that responsibility. Did that just seem like the right thing to do or did you have to think carefully about it...?

YP: No, I mean with, if you want freedom, with the rights come responsibilities. You can't have one and not expect to have the other.

FM: For you, you were completely comfortable with that?

YP: I can understand why people may have to think long and hard about what they do, but for me it was just...I had spent so long in institutionalised settings...I wanted to, I wanted the chance to be the individual that I was and not be cocooned or restrained by the gatekeepers or what appears to be an antiquated system. I had already proven to people that I could live on my own with support so then why didn't I have the rest of my life. (FM: yeh). Why couldn't I choose to do what I wanted?

FM: These are really good examples that you are giving. I am keen to find out more about how you make choices. You said that self-directed support was for you. How then did you go about identifying or choosing an agency to support you.

YP: I was in a bit of a crisis situation where one agency had dropped me and I was studying at university and I found myself with an agency that I had never worked with but I got on with a couple of members of staff that I saw regularly, and I liked the way they worked and their ethos. OK they f*** up sometimes, but what agency doesn't. [Background noise: 40 seconds]. If it doesn't work you move on. It wasn't so much choice as necessity, but I have fallen on my feet as it were. As much as the agency has its flaws its good points outweigh the bad. [Background noise obscures 30 seconds of recording]. In a way going back to the choices thing, I wasn't given a choice...a good choice fell into my lap (laughs). [Background noise obscures 20 seconds of recording]. I don't do meetings. As I say what normal sane person has a meeting just to change one aspect of their life: "you kidding...your days of having me as your institutionalised spastic are over, I'm done, I want to live, not just exist".

FM: So how have people responded to your wish not to have meetings? Do they still have them without you, or...?

YP: They wouldn't dare. They wouldn't dare. They have a file on me but they are not allowed to bring it anywhere near me. Because I don't do files, because a file will only tell you so much. [Background noise: 15 seconds]. They don't like it because they like to medicalise, quantify, and make it difficult, but what about my life? [Background noise: 30 seconds].

FM: Have you found over the years that people are keener to talk about problems rather than strengths or solutions?

YP: Oh, yes. But if they can't figure it out, they can't work out how you can figure it out. Because they can't come up with solutions, then when you come up with solutions they go 'oh, where did that come from?' You know what I mean though? It's no rocket science.

FM: Tell me, with your experience, if you were advising a young person who was say 18 and about to leave school, and needed some kind of support, you know some kind of help from social work or social care, what kind of advice would you be giving them?

YP: It depends if you are on your own or with someone. [Background noise: 10 seconds]. I would work with someone they feel comfortable with and I would work with the two parties together. And what I say is find out where they would be, [background noise; 30 seconds]. It is about them feeling comfortable and you will probably get more out of them and a realistic and honest answer because they feel comfortable rather than what they think you want to hear.

FM: Sure, yeh. And you have talked about in some ways how some of the choices have fallen into your lap. (YP: I have been very fortunate). But what, can you say what you think about how people make choices. Do they have to experience things to make choices, or can they read about it, visit a place?

YP: It depends on what you have the capacity to do. I suppose if you wanted to, if you want someone to assist you, you can go onto Google and get the people from there to help you that way. I am a very old school person. If I want to go and see something I will see it. I like people, don't get me wrong, but I would rather go and see it.

FM: So you think it is important that you experience things?

YP: I would be a very different person if I didn't go to uni'. Uni' gave me the extra spear that I didn't have before, so I think it's important to go and check out these places, but I think it's important to respect that although that is me it may not be everyone's cup of tea. If they want to do it another way, they can do. The best way I can find out is to go and do it. I have scared the living shit out of people because I have gone in and done it. When I did my degrees people up here were shitting themselves, because on my own for whatever reason, I am going to do this.

FM: But you personally, did you feel that you needed to discuss choices before going ahead. Some people do like to check things out with other people, and others just like to make their own decisions.

YP: When I am really unsure about something I will ask people. I surround myself with people who know me. I am going to make the decision, but 'help!' [Background noise: 17 seconds]. At the end of the day, I will make the call. But if you can get other people's views, their take on it, to see where they come from, because they may be able to see aspects that I may not have thought of. {Background noise: 22 seconds}.

FM: Last question. Is there anything else that you feel we have not covered?

YP: All I would say is when people make choices, be aware of the consequences of your choices. Every action has a consequence and as long as you can take that on board then [background noise: 8 seconds]. I don't need to be cared for, I need to be supported to be allowed to live the life that I choose to live. If I needed care I would be in a high dependency unit (laughs) but I am now in a position to go out there safely. It is not just about living your life; it is about knowing your limits and having respect for your abilities. SDS should be an addition or an enhancement to your level of independence or interdependency. It doesn't matter whether you are disabled or not, when you strip back life we are all interdependent. I know I will be interdependent for all my life.

FM: Thank you [YP name]. I am going to put this off now.