How has having a sibling with SLD/PMLD impacted the lives of typical individuals? A birth order study.

Annabel Cook

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DECLARATION

I hereby declare that this dissertation is the result of my own independent investigation, except where I have indicated my indebtedness to other sources.

I hereby declare that this dissertation has not been submitted or accepted in substance for any other degree or academic award, nor is it being submitted currently for any other degree or award at any institution.

Annabel Jessica Cook
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Many thanks to all the participants who were kind enough to take the time to help me complete this research, which I understand is a very sensitive topic. With thanks to Kerry Cook, for proofreading every word of this project and the tutors that gave me the skills and knowledge to complete this degree.
Abstract

This report studies the views and experiences of typical siblings of individuals with Severe Learning Difficulties (SLD) or Profound and Multiple Learning Difficulties (PMLD) and explores the effects of birth order on these experiences. An online questionnaire is used to collect data from 27 participants. The findings show that older siblings feel they have a better relationship with their sibling with a disability, feel their social life is more affected by their sibling and have more concerns than younger siblings. Common concerns among both groups of siblings are the care their sibling is receiving, what the future holds for themselves and their siblings and the funding that their sibling receives. The study adds to the existing bank of literature on the experience of siblings of individuals with SLD/PMLD and expands the small research area of birth order effects. The findings have the potential to be used in a range of settings in which a holistic family approach needs to be used.

Key words: Sibling Experience, Severe Learning Disability, Profound and Multiple Learning Disability, Birth Order Effects.
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Chapter 1 – Introduction

The purpose of this study is to gain a deeper understanding of the experience that typical adult individuals have when they have a sibling with Severe Learning Difficulties (SLD) or Profound and Multiple Learning Difficulties (PMLD) and how birth order affects these experiences. SLD and PMLD are umbrella terms for a range of different conditions and disorders, namely any which cause serious learning difficulties, communication difficulties and in some cases movement difficulties, sensory difficulties or physical disabilities. No two individuals with SLD/PMLD will have the same specific areas of need, but will generally be characterised by severe difficulties in the aforementioned areas. The study will focus on individuals over the age of 18 in the UK only.

This area of research has been chosen because family experience is a growing area of research and is not yet fully saturated and the area of sibling experience of individuals with profound learning difficulties is particularly under-researched. As this research will focus on adult siblings only it provides a perspective that is entirely different to studies which focus on sibling dyads in infancy, which obviously explore a completely different set of issues. Additionally, the study will have a specific focus on the effect of birth order on sibling experience, a field in which there is limited research currently and so it will hopefully build the knowledge base on the complex area of sibling experience. The current issues in this field of research, especially where adult siblings are being researched, centre on the caring duties of siblings (Dew et al., 2008; Coyle et al., 2014) and the negative experiences of typical siblings. This study seeks to avoid focussing on these areas and instead investigate areas such as the relationship between the typical and non-typical siblings and the typical sibling’s experience of their social life.

The importance of this area of research is paramount, because although parental experience of disability is well documented, sibling experience is less thoroughly considered in academic literature, leading to a vital part of the family not having their views and experiences accounted for, both in academic literature and by extension in the everyday practice of professionals.

This study could be used for a variety of reasons and is not aimed at any one particular
profession or organisation. It should be considered that the study could be used in almost any setting in which young adults or adults with SLD/PMLD and their families are included, such as day services, care facilities and therapy teams. Considering the needs, concerns and experiences of typical siblings has the potential to improve any service in which the family of an individual with SLD/PMLD is involved as it can provide a holistic view of the family and therefore a more co-ordinated service.

The research questions that were determined for the research are as follows:

How has the typical sibling’s social life been impacted by having a sibling with SLD/PMLD?
Does the birth order of the sibling affect this?

How do the typical siblings feel about the quality of their home/family life? Does the birth order of the sibling affect this?

What concerns do the typical siblings have for themselves and for their siblings? How are concerns different for older and younger siblings?

How do the typical siblings rate the quality of the relationship with their sibling and what factors affect this? Does the birth order of the sibling affect this?

The research will endeavour to answer the questions as thoroughly as possible through the medium of a questionnaire.
Chapter 2 – Literature Review:

There is currently a moderately sized bank of literature on the topic of siblings of individuals with disabilities with a range of different focusses. Although the focus of this research is on the effect of birth order on the experiences of typical siblings this review of the existing literature will examine research from all aspects of the field of typical sibling/sibling with SEN/D literature, beginning with an overview of sibling experiences of living with a sibling with a disability, moving through the specific challenges that siblings face and then focussing finally on birth order and PMLD/SLD specific research. Although current research was sought out, some of the research used is dated, which may affect the transferability of the themes raised in to today’s society due to advancements in areas such as technology which has aided the development of communication tools for individuals with SLD/PMLD and a change in the perceptions of disability. However, dated research has only been used here where it is understood that the themes of the research are useful in the context of the current time. As most of the research in the area of sibling experience of disability is so dated, the research to be carried out will aim to fill a gap in the knowledge of how siblings are affected in the current environment, and aim to add to the small existing knowledge base around this topic.

2.1 The Positive and Negative Aspects of Having a Sibling with a Disability

Within the field of sibling experience the evidence seems to show that sibling perceptions of the impact of disability can be wide ranging; from overwhelmingly positive to considerably negative. The positive effects of living with a sibling with a disability are well documented and include the sibling: being more accepting of difference and diversity in others, having an expanded social network due to community involvement, deriving joy from spending time with their sibling, having an increased sense of spirituality, developing personal strength and having a positive impact on others (Stalker and Connors, 2004; Stainton, 1998). It is suggested that the positive attitude of siblings is in part due to the negative views and the stigma of society surrounding having a sibling with a disability not being recognised by the child until after a
sense of normality is instilled securely in the child (Burke, 2004). Conversely, other research finds that social networks are largely closed to those who have a sibling with a disability and their participation in social and community networks can be limited for a number of reasons, including the socially undesirable behaviour of the person with SEN/D (Bristol, 1984; Whitaker and Preece, 2013). The reason for the contradiction in the findings of this type for research may be due to the type of condition or disability that each study investigated. For example while Whitaker and Preece (2013) and Burke (2004) examined families with members on the autism spectrum, Stainton’s research focussed on the impact of intellectual disabilities. Therefore, it must be appreciated that not all the research in this areas will be directly pertinent to the study being undertaken due to the differences in experiences based on the disability of the sibling but each study has value in exploring the sibling experience as a whole.

The research that will be undertaken in this project will seek to explore the experiences of siblings of people with PMLD/SLD, be they positive or negative, with regards specifically to the impact on their social life and their experiences of home and family life, to add to this area of research and provide a PMLD specific view. The experiences of siblings of people with PMLD/SLD could be considered to be unique from sibling relationships where one sibling has a minor SEN/D, in so much as the severity of the sibling’s disability is profound and complex and has such an acute effect on the individuals around them that it is bound to affect their lives and experiences.

2.2 Relationships between Typical Siblings and their Sibling with a Disability.

The two primary features of sibling interaction as stated by Dunn (1983) are reciprocity and complementarity, which may not be as prevalent in sibling dyads where one had PMLD/SLD due to the communication difficulties which are associated with the condition (Goldbart et al., 2014). The literature on the topic of sibling communication where one sibling has a significant language delay, as is likely with people with PMLD/SLD, seems to suggest that typical sibling often has considerable difficulty engaging in communicative interactions with their sibling, sometimes resulting in stunted relationships (Singh et al., 2015). The reasons for
these lacking relationships are varied and both the typical sibling and the sibling with SEN/D appear to share responsibility.

It has been suggested that typical siblings, especially when young, have trouble identifying communicative behaviours in their sibling (Singh et al., 2015) and as they grow older it is more difficult for them to interact meaningfully with their siblings as they are balancing the responsibilities of a busy life, although they often display a desire to maintain a relationship with their sibling (Tozer and Atkin, 2014). Additionally, when the sibling with SEN/D is young they may not be able to play in the same ways as their sibling and as such the relationship is lacking from an early age (Gallagher et al., 2006). As both siblings age the views of the literature differ on what factors on the part of the sibling with SEN/D affect the relationship. For example, Rimmerman (2001) suggests that when the sibling with SEN/D has a high level of independence a positive relationship is more likely to be sustained, but this is contradicted by Prunchno et al.’s (1996) study which found that when the typical sibling provided more support to the sibling with SEN/D because they were less independent the siblings had a better relationship because of this extra time spent together. It should be considered that these differing findings may be purely due to the personalities of the individuals in the studies and more research in this area investigating other variables simultaneously may be valuable.

Authors suggest that other external variables impact the development and the maintenance of the relationship. The geographic location of the respective siblings is often cited as one of the most significant factors in the involvement of the siblings in a meaningful relationship (Rimmerman, 2001; Seltzer et al., 2001). This may be significant as when the typical siblings age and move away from the family home where their sibling is likely to still live, they may be inhibiting the relationship.

Furthermore, Doody et al., (2010) reports that siblings of people with PMLD/SLD describe relationships with significantly lower levels of ‘warmth’ compared to siblings dyads in which neither had a disability or where one has a mild disability. Although Doody et al. do not speculate as to why this is the case further than suggesting that it may be due to the lacking communication between the siblings, the previously stated research may provide an insight into the possible reasons for this difference. Through the research that will be conducted it is hoped that sibling relationships will be more deeply investigated, focussing how the typical
siblings rate the relationship with their sibling, to determine which factors most predominantly affect sibling relationships, in their own opinion, as the literature appears to be lacking in this area.

2.3 The Roles of Siblings

The roles of typical siblings may be significantly changed from the average sibling roles that are fulfilled by sibling dyads where neither has a disability, due to the severity of the disability and the possible need for continual care.

The literature reports that many typical siblings may take on the role of carer for their severely disabled sibling when the main existing carer can no longer take care of the sibling (Dew et al., 2008; Coyle et al., 2014). Dew et al. (2004) suggest that siblings actually begin to help with the caregiving responsibilities from a young age, a finding which is further substantiated by research which suggests that 80% of siblings contributed to the care of their siblings every day (Burke, 2010) and older research which has found many of the same trends (Adridge and Becker, 1994; Beresford, 1994). Saxena (2015) expands on these ideas and suggests that during the typical sibling’s young adult years, the act of caring for their sibling may distract and distance them from their social life and so they tend to avoid the task but as they age and settle into an independent life they accept their responsibility over their sibling and provide more contact and support.

Research into other aspects of the roles of siblings in the family environment has found that the parents of children where one has a disability and one does not, report that there is a significant disparity in the power and status of the children, with the typical sibling being perceived by the parents as being most ‘powerful’ (Bischoff and Tingstrom, 1991). Furthermore in this study the siblings themselves disclosed that they felt that their mothers favoured their siblings. Methodologically this study raises some valid issues surrounding the usefulness of parental vs sibling reports on sibling relationships and roles. Although using both views may produce a more holistic view of the situation, it could be argued that the siblings in question have the most direct experience of their relationships and roles and so should be the main focus of an investigation on the experience of siblings. In the study to be undertaken the views of the typical siblings will be the only ones considered as research in
the field of disability in families shows that parents tend to report the effects of disability on
the family and the typical sibling more negatively than siblings themselves did (Kao and
Plante, 2004).

2.4 The Emotional Impact of Having a Sibling with a Disability

Research suggests that the emotional state of the typical sibling and their quality of life can
be affected in a wide range of ways due to their sibling’s disability. Rosetti and Hall (2015)
found that siblings report significant levels of stress due to their current or future caregiving
responsibilities, due to the toll it takes on their own lives. They also report that when young
adults left home they experienced feelings of guilt due to having less contact with their
sibling and family. Furthermore, Goudie et al., (2013) suggest that living with a sibling with a
disability impacts upon the typical child’s interpersonal relationships, school performance
and use of leisure time, resulting in them being considered ‘functionally impaired’. They
propose that these negative impacts can be counteracted with the use of appropriate
interventions so that the typical child can keep pace with their peers, both socially and
educationally.

The negative experiences, emotions and possible social adjustment difficulties that typical
siblings face are correlated with many different factors. They are most strongly correlated
with parent and family factors, such as parent stress and time spent together as a family,
rather than the sibling’s personal stress (Giallo and Gavida-Payne, 2006). Moyson and
Roeyers (2012) expand on these findings; the typical sibling’s quality of life is impacted by
factors which are not related to the family or their immediate environment, such as the
amount of private time they get, mutual understanding and acceptance. Other factors that
may influence the typical sibling’s behaviour are family cohesion, knowledge of the sibling’s
disability and self-esteem, among others. Lack of any of these results in an increased risk of
the typical child having behavioural problems related to their family situation (Williams et al.,
2002).

Once again, each of these studies focuses on a different sub-section of families with a child
with a disability, such as chronic illness or developmental disability, which may account for
the difference in the findings of which factors are most prominent in combatting negative sibling emotions.

2.5 The Effect of Birth Order on the Sibling Experience

As the main focus of this study is to compare how the experiences of younger and older siblings of people with PMLD/SLD differ, this section will explore the research around the effect of birth order on sibling’s lives. Not all the research explored in this section is specifically related to PMLD or SLD but many of the ideas and issues raised are transferable to all types of disability. The study to be conducted will fill the gap in the literature about how birth order affects the experiences of siblings with PMLD/SLD specifically. As mentioned earlier, the literature in this section is dated, which may affect its transferability, but it is still valid research which provides an important base of knowledge.

In a study focussing on sibling dyads where one sibling has cerebral palsy, several interesting findings were presented about the roles of siblings in these kinds of relationships. Firstly that the sibling with a disability took on the role of ‘younger sibling’ regardless of birth order and subsequently the asymmetries and disparities between the siblings increase as the pair age, with the opposite being true for typical sibling dyads (Dallas et al., 1993). Additionally, Begum and Blacher (2011) found that status and power within the relationship was not affected by birth order of the siblings. Furthermore, in Dallas et al.’s study, the findings also presented specific information on how birth order effects the communication between the siblings, with the younger typical sibling often losing interest in social engagements with their older disabled sibling. These findings build on the research previously mentioned in the ‘Relationships...’ section; highlighting that variables such as birth order can be important to consider when researching aspects of sibling relationships.

In addition to communication and relationship issues, the negative effects of disability on younger typical siblings are well documented. Younger siblings tend to surpass their older sibling with a disability in terms of development in almost every area, especially in dyads where the sibling has a severe disability, which leads to feelings of guilt in some siblings (McHugh, 2003). Mothers of children whose first born has a disability tend to place more expectation on the younger siblings (Epstein et al., 1980), which, it could be speculated,
would place the younger siblings under pressure and stress.
Additionally to this, gender appears to be a factor in sibling experience. When the younger sibling is male they score more highly on psychological impairment scales than their older male counterparts, although the same study showed that younger female siblings were often more well-adjusted than older female siblings (Breslau, 1982). Previously to this research Garth’s (1974) findings suggested that there was no difference in social disadvantage or problem behaviour between older or younger siblings. These studies seem to contradict each other but both highlight the need to consider all possible variables when analysing the effect of birth-order; such as socio-economic status, gender and family size. These studies do not go into depth about the reasons for the differences in experience due to birth order, gender and psychological differences, so more research into the reasons for these differences may be beneficial.

The experiences of older siblings can be mixed and there appears to be less literature on their experiences specifically. Older siblings most often report differential treatment in favour of their younger sibling with a disability, are reportedly more aware of differences between them and their sibling (Pit-Ten Cate and Loots, 2000) and are expected to, and subsequently do, spend more time caring for their sibling than younger sibling’s do (Seltzer et al., 1991).

2.6 Conclusion

As mentioned, some of the literature used in this review seems outdated as the research was conducted several decades ago, this seems to be a prominent issue in the research in the area of sibling and PMLD/SLD research. Much of the relevant research on the topic was conducted in a time when the communication of people with PMLD/SLD could not be assisted with assistive technology such as iPads and eye gaze technology and so the worth of the research in the modern world must be questioned. Despite this it gives an insight into the lives and experiences of sibling dyads and exposes issues that can be applied to the situation that siblings of today are still experiencing.
Overall, the research that will be undertaken during this project will add to the bank of modern literature which reviews the situation for siblings in a time when people with disabilities are assisted through technology and sibling support groups are more available.
than ever before. Because it will focus specifically on birth-order influences on sibling relationships, it is expected to fill the gap in the literature regarding older siblings, and explore in more depth the home and social lives of siblings and the concerns that siblings have for both themselves and their families.
Chapter 3 - Methodology:

During this chapter the way the research was conducted will be explored in relation to literature on best practice for this type of research. Several areas will be explored: the paradigm, methodology and method that was used, how the data was collected, the time frame of the research, successes limitations of the research, the sample used, the validity and reliability of the study and the ethical issues associated with the study.

3.1 Paradigm, Methodology and Method:

This research was conducted under and interpretivist paradigm focussing purely on the views of the siblings themselves, with the focus being on the feelings of the siblings and not a comparison with a control group of typical/typical sibling dyads. There are many documented weaknesses and strengths of the interpretivist paradigm. Black (2006) states that the main strength of the interpretivism compared to positivism is that it can properly capture and address the complexity of a situation, which is the intended purpose of the research. However, Bunniss and Kelly (2010) suggest that interpretivist studies can never be bias free due to the qualitative nature of the data gathered which can be easily influenced by the researcher themselves. Researcher bias has been avoided as much as possible both in the collection phase of the study through the use of internet surveys, which will be explored later in this chapter, and in the analysis phase by analysing the data from a neutral frame of reference. In the interest of truthfulness and full disclosure it should be kept in mind that while the researcher is passionate about this topic, they have no specific vested interest in the results or the participants.

The overarching methodology of the study was a simple survey, which will cover a larger area and number of participants than other methodologies such as case study, and because of this it has been deemed the most appropriate system. Self-administered questionnaires were used due to the need to collect both quantitative and qualitative data from a large quantity of people which other methods such as interviews or documentary analysis would not allow for. Research suggests that self-administered questionnaires provide the participants with an
increased sense of privacy (Vehovar and Manfreda, 2008), which for the purposes of this study was deemed important due to the personal nature of the information to be gathered. The questionnaire was distributed online through social media, both by the researcher personally and on their behalf by certain PMLD publications and support organisations. Online collection methods were used rather than paper due to the speed at which online results can be collected and the ease with which they can be distributed.

Online research is a relatively new method of research, and literature show that there are clearly some advantages and disadvantages. Vehovar and Manfreda (2005) state numerous advantages such as the lessened cost and the almost complete absence of interviewer bias which leads to a better quality of data. Participants may also be more open with their responses than in traditional paper questionnaires, and a wider geographical scope is possible, allowing a more diverse sample (Comley and Beaumont, 2011).

Conversely, Denscombe (2010), notes that web surveys rely on participants finding the page which can be combatted by sending out the questionnaire via e-mail, or social media as I will be doing. Online research does not appear to alter the results of a study as Bryman (2012) collates the findings of many social sciences studies and found that the delivery method, web or paper, of the questionnaire does not influence the results obtained, due to the nature of both being completed privately. There are many ethical issues surrounding the topic of online research which will be discussed in ‘3.5 Ethics’.

The questionnaire was piloted before being sent out, which allowed for some questions to be changed to be more accessible and clearer. Two individuals were contacted to take part in the pilot survey, both of whom have siblings with PMLD and are known personally to the researcher. From the pilot it was gathered that the individuals felt there were some aspects of their experience which were not fully covered by the first draft questionnaire, therefore some questions were added and some clarified. The results from the pilot study were used solely to improve the questionnaire and the responses were not counted towards the data analysed in this report.
3.2 Successes, Limitations and Improvements:

The study managed to reach a larger sample population than was expected in the limited time frame of the study. Data from 27 participants was collected, which was a significantly larger than the expected sample.

The study also collected a useful amount of both qualitative and quantitative data from the participants, which gave a general well rounded view of their experiences. However, methodological triangulation where the questionnaire and additional interviews were carried out simultaneously may have provided more background for the participant’s responses and provided contextualisation of their answers, allowing for data analysis to rely less on inference.

Although the pilot study assisted in improving the questionnaire a significantly more rigorous piloting process may have been valuable to the study as it may have improved the questionnaire further, as upon reflection there were some aspects of the sibling experience which were not covered fully or in enough depth to be satisfactory. Specifically the section of the questionnaire focussing on siblings’ experiences of family life and social life, in which qualitative questions are not included resulting in a lacking examination of these particular aspects.

3.3 Sample:

The population that the research focussed on was ‘adult siblings of people with PMLD/SLD with no additional needs of their own, living in the UK’, and due to the generally undocumented nature of this group it was deemed impossible to survey the entire population, and due to time constraints this could not have been attempted, a common issue in studies such as this (Fricker, 2008).

The participant group was defined by having the parameters of ‘over 18’, to negate the need for parental permission and ‘living in the UK’, to avoid different experiences based on different policy, culture or attitudes. Which resulted in a more focussed group of views and experiences and less

Purposive sampling was used in this study. Members of the sibling community were selected to participate in the study via the method of sharing the questionnaire on social media and
sending it directly to some siblings who were known to the researcher. This method was used due to the specific parameters set on who could participate in the research; typical siblings over the age of 18 living in the UK with a sibling with SLD/PMLD. It was expected that purposive sampling would be the most appropriate way to collect the data needed. An explorative sample was sought out, rather than a representative sample, due to the aims of the research; to find out about specific participant’s views rather than create findings which represent the entire population of people with siblings with PMLD/SLD (Denscombe, 2010).

It has been considered that a number of the participants may be personally known to the researcher, but as the questionnaires are delivered without any researcher contact, and the responses are completely anonymous, any personal relationships should not impact on the results of the research.

3.4 Validity, Reliability and Trustworthiness

The validity of the research was ensured in several different ways. Internal validity, how well a study considers variables which may affect the results and eliminates them (Thomas, 2013), is hard to establish in social sciences research such as this, but all variables which may have affected the results were taken into account, such as the gender and age of the respondent. Experimenter effects and the experimenter’s positionality must also be considered in social research (Silverman, 2013). By using a questionnaire experimenter effects should be kept to a minimum as there is no back and forth responses as there would be in an interview. By avoiding leading questions, experimenter effects should be kept to a minimum, if not eliminated altogether. With regards to experimenter positionality, the experimenter in this study had no vested interest in the results of the study and was in no way involved in the production of the data. The data was analysed as objectively as possible, although it could be argued that this is almost always impossible as the researcher will always view the raw data through their own experiences. As with any interpretivist research the researcher’s bias was considered and was avoided as much as possible. Validity was further increased by the nature of the questionnaire distribution which meant
that the participants were not selected by the researcher, and so could not be expected to display any particular characteristics (Flick, 2007).

Similarly to validity, reliability was also considered thoroughly through the research process. However, as Thomas (2013) mentions, the concept of reliability is hard to apply in interpretivist research as any method in a piece of social science research is likely to produce different results each time it is conducted due to the very personal nature of the research and the unique feelings of the participants.

Truth in the documentation and reporting of findings is essential for an interpretivist study to be truly ‘reliable’ which can be achieved by having accurate transcriptions where interviews or observations are being used (Silverman, 2013). However, as questionnaires are being used, rather than a method where transcriptions are necessary, the raw data will be accurate as it has come directly from the participants. Additionally, all aspects of the raw data will be considered and analysed so that the results and discussion truly reflect the views and experiences of the participants, even the less common views.

3.5 Ethics:

As with any research project, the BERA (2011) ethical guidelines were considered throughout the planning stage and followed during the research and analysis.

Informed consent was obtained from the participants by attaching the consent letter at the beginning of the questionnaire (see Appendix One). By continuing with the questionnaire after having read the information and consent letter, it was assumed that the participants had understood the research and were consenting to taking part.

Participants had the right to withdraw their information up until the 20th of March. This was achieved by asking the participants to provide a code on their submitted questionnaire that was unique to them, in this case the code was comprised of the participant’s initials followed by their date of birth. It is stated in the consent letter that the participant could contact the researcher and quote this code to withdraw from the study, or similarly, to be debriefed about the study after it had been completed, which one participant wished to participate in.

With regards to ‘detriment arising from participation in the research’, the information that the participants are asked to provide on the questionnaire directly relates to aspects of their
lives which are very personal and could raise negative emotions. There is a chance this could cause temporary negative impacts on the participants, but this has been counteracted by the statement at the beginning of the questionnaire stating that the participants do not have to answer any questions which they do not feel comfortable with (Lee, 1993). Despite their sensitive nature, it was deemed that the questions were all necessary for the collection of appropriate data, and so they were not removed from the questionnaire. Furthermore, the pilot survey results yielded data that suggested that the sensitive questions were indeed important and should not be removed from the finished questionnaire.

Anonymity and confidentiality were considered paramount in the research. However, online research raises several issues in this area. It is stated that during online research complete anonymity is unlikely to be viable as all information, such as their IP address, is stored somewhere, and it is sometimes possible for other participants or the public to see data (Bryman, 2012). However, Oliver (2010), notes that avoiding names or assigning the participants false names helps to protect anonymity and McKee and Porter (2009) add that control can be maintained in online research by setting up a separate forum for research specifically. Both points of advice were adhered to in the research.
Chapter 4 - Results and Discussion:

In total the study recruited 27 participants, 14 of which were older siblings and 13 of which were younger siblings.

The constant comparison method was used to collect themes that emerged through the qualitative aspects of the study and network analysis was used to group together important themes and sub themes (Thomas, 2013). An example of the coded data is evidenced in Appendix Two, at a stage before network analysis was completed. For the quantitative data that was collected, percentages and averages were calculated. All averages were calculated using the mean. During the process of coding and analysis, the themes that emerged were complex but 4 over-arching ideas were identified: sibling relationships, the impact of a sibling with SLD/PMLD has on family and social life and the concerns of typical siblings.

For the purpose of this chapter, participants will be referred to as YS# or OS#; Younger Sibling No. or Older Sibling No. For more information about other dimensions of the participants’ lives refer to Appendix Three, in which tables detail other aspects of the participants such as their age, and if they live in the same home as their sibling. Although this information is not necessary to understand the following results and discussion, it may help to contextualise the experiences of the siblings.

4.1 Relationships:

The participants rated their relationship with their sibling with SLD/PMLD on a scale of 1-10, with 1 signifying ‘Very poor, no relationship’ and 10 signifying ‘Very good, close relationship’. The mean average rating that older siblings gave their relationship was 7.2, while the younger siblings rated their relationships slightly lower at 6.6. There could be many possible reasons for this difference in the views of the siblings, but the study did not explore these explicitly and so only a passing reference will be made to them as no conclusions can be drawn from the data collected. Four relationship-centred themes emerged from the data collected from the typical siblings. These were communication, shared interests, geographical proximity and
4.1.1 Communication:

Literature suggests that the sibling with a disability’s ability to communicate in a typical and understandable way can impact significantly on the relationship between the typical sibling and the sibling with SEN/D (Singh et al., 2015).

Two younger siblings in particular explicitly mention the communication barrier between themselves and their sibling, but in strikingly different contexts. While YS11 states that his brother cannot communicate “directly” with him, he scores their relationship a 10 and explains that his brother is a “joy to be around”. Conversely, YS12 states that his brother “can’t really communicate with me in any way” and scores their relationship a 3 with the explanation being that it is unclear whether his brother recognises him at all. Clearly the barrier to communication that people with SLD/PMLD face can be a challenge to their sibling relationships, but from this small extract it appears that it is not necessarily always the case. There could be many factors other than their sibling’s communicative abilities influencing their relationship such as how much time they spent together as children when the relationship was being formed and how many interactions they have now as adults. YS11 lives with his sibling while YS12 lives away from his sibling which may contribute to the amount of meaningful interactions they can have and therefore impact their relationship. Alternatively, other factors which were not investigated, such as the family’s and the individual’s view of disability, may have influenced the relationship, although this is speculation and would need further research to confirm.

Furthermore in the data collected, some siblings expressed a desire to spend more time with, or communicate more with, their sibling which was not always possible due to their sibling’s communication difficulties. This is an issue which is already examined in the existing literature. Tozer and Atkin (2014) note that many siblings express a desire to maintain high levels of contact with their sibling throughout their adult lives, and the participants seem to confirm this. For example, OS5 mentions that he wishes to keep in touch with his sibling
regularly to maintain their positive relationship but it can be a challenge as when he is away from the family home there is very little opportunity for interaction as a phone call would not be suitable. Issues such as this, where communication is a barrier, may be aided by new technologies such as Skype and Facetime so that there is both visual and audio stimuli, aiding dyad relationships where verbal communication is a challenge for one partner.

4.1.2 Shared Interests:

Another trend that seems to appear in the data is that sharing interests and spending time together appear to be conducive to a good sibling relationship. 6 out of the 10 siblings, both younger and older, who gave their relationship a rating of 10 cited shared interests or spending time together as a factor in the quality of their relationship. Some, but not all, of the time spent together was based around care with most of the comments about spending time together centring on spending leisure time together sharing interests such as video games and music. YS10 mentions that she and her brother “bond together over music and films” and although she has given their relationship a rating of only 4, she opines that this shared interest in leisure activities has improved their relationship. Alternatively, YS4 mentions that she believes that her sibling relationship was improved by taking on caring activities and “helping” her sibling. It appears that spending time together, either in a caring capacity or leisure capacity, helps to improve sibling relationships and is an essential part of a positive sibling experience with even participants who gave their relationship a very low score citing spending time together as a highlight of their relationship. These findings give an insight into ways that sibling relationships could be improved and could therefore be useful in settings such as family therapy.

4.1.3 Geographical proximity:

Within the existing literature on the topic of sibling relationships, geographic location of the respective sibling is a component factor in the success of the relationship (Rimmerman, 2001; Seltzer et al., 2001). However it seems that in this study there was little to no correlation between whether the typical sibling lives with their sibling with SLD/PMLD or not. While younger siblings who lived with their sibling all of the time or some of the time rated their
relationship more highly than those who lived away from their sibling, older siblings who lived with their sibling some of the time or not at all rated their relationship more highly than those who lived with their sibling permanently. No significant conclusions can be drawn from the data in the instance and a study with a larger sample investigating this topic specifically may lead to more conclusive results.

4.1.4 Accepting challenging behaviour and feelings of stress:

Accepting the challenging behaviour of their sibling was a recurring theme in the older sibling’s data and although it did not always predict a highly scored relationship it highlights an issue that older siblings seem to feel is important. Interestingly, acceptance of behaviour does not appear in the comments of the younger siblings. It is unclear why this subject was raised only by the older siblings.

Evidence of ‘feelings of stress and frustration’ are evident in 3 of the 12 younger sibling accounts, whereas there is no mention of stress in the older siblings’ narratives. This study cannot conclude conclusively why this trend has emerged but Epstein et al (1980) comment that when a mother’s first born child has a disability they tend to place more expectation on the younger, typical sibling; possibly resulting in the stress and frustration found in the data. Additionally, Rosetti and Hall (2015) suggest that siblings experience feelings of stress due to their current or future caregiving responsibilities, although it is unclear in this instance why younger siblings specifically would express more feelings of stress than older siblings.

These particular topics may have had more potential for deeper analysis if the categorisation of the disability which the sibling with SLD/PMLD has had been taken into account, as it may have allowed for better understanding of the sibling’s opinions, or if the study allowed for the collection of more specific qualitative data on this subject. Further study into these trends in the data may help to clarify the reasons behind the experiences of this particular group of siblings.

4.2. The Impact of a Sibling with SLD/PMLD on Social Life

The questionnaire used asked about many aspects of the social life of the typical sibling and how much they were affected by having a sibling with SLD/PMLD. This section covered areas
such as ‘going out with friends’ ‘making friends’ and ‘maintaining romantic relationships’ among other aspects.

Older siblings rated each ‘social life’ area more highly affected on average than the younger siblings, with the biggest disparities in making and maintaining friendships. Both younger and older siblings rated ‘going out with friends’ as being the most highly affected area. ‘Personal finances’ was rated as least affected on average by both younger and older siblings.

The trends that emerge in the data were not substantiated in this study by qualitative data, so conclusions cannot be drawn as to why the typical siblings felt that certain aspects of their social lives were affected by their sibling or, indeed, whether these effects were positive or negative.

Drawing on the existing literature it is clear that a typical sibling’s experience of a social life can be vastly different depending on several circumstances. For example, typical siblings tend to be distracted from their social life due to real or perceived care giving responsibilities (Saxena, 2015) and a lacking social support network that can be a consequence of this can lead to wellbeing and mental health problems (Lovell and Wetherell, 2016). Stampoltzis et al. (2014) note that at in their youth typical children do not experience negative effects on their social life due to their sibling with a developmental disability, which suggest that if social life is affected significantly at all, it begins in adulthood.

4.3 The Impact of a Sibling with SLD/PML on Family life

On average, family life components were more affected than social life components for both the younger and the older siblings. Both older and younger siblings rated family life aspects very similarly. ‘Going out as a family’ was rated as the most highly affected family life component by both groups of siblings and ‘the relationship between [participant] and [participant’s] parent/s’ was rated as second most highly affected component in both groups of typical siblings.

Family Quality of Life (FQOL) is a concept in the study of Intellectual Disability (ID) which encapsulates the experience of the family including a member with a developmental disability covering areas such as physical, emotional and material wellbeing, the relationship
between the individual with an ID and their family and the impact on the family as a result of ID (Brown et al, 2009; Gardiner and Iarocci, 2012). While the concept of FQOL can be easily applied to this study, with the family life components that were measured being potential aspects of FQOL, no specific conclusions can be drawn due to the relatively small participant pool and some aspects of family life not being measured in the study. However, broader conclusions could be drawn from the data collected. Although the experience of family life is significantly different for each family with a member with a severe intellectual or physical disability, younger and older siblings seem to experience family life in much the same way and aspects of family life such as ‘going out as a family’ are almost universally affected by having a sibling with SLD/PMLD.

Of course, these findings cannot be extrapolated to predict the views of all typical siblings, but the data seems to suggest that the experience of ‘family life’ was not radically different for younger and older typical siblings suggesting that birth order was not a deciding variable in this aspect of sibling experience.

### 4.4 Concerns of siblings

Concern for one’s family is a natural part of growing older and for typical siblings this can be exaggerated due to the nature of their sibling’s disability and the complexity of their needs. Within the study, the concerns of the siblings were measured in a tick-box manner which was followed up with the opportunity for the siblings to express themselves further in a qualitative format.

All the siblings apart from one younger sibling expressed concerns for their sibling, themselves or their family. On average, older siblings had more concerns than younger siblings. It may be considered that this is because they were biologically older, and more emotionally mature than the younger siblings, and so were facing the worries of their parents passing away, or were more aware of the systemic issues facing them and their sibling, but in this study the ‘older siblings’ were not significantly biologically older than the ‘younger siblings’. It appears then that there is no definitive explanation for why older siblings have more concerns, other than personal or experience based factors.
4.4.1 Future Care

As the siblings grow older there is an expectation of the typical sibling to provide continued care for their sibling as their current caregivers pass away or become too frail to provide care. This is the experience of many typical adult siblings (Dew et al., 2008; Coyle et al., 2014). The collected data suggests that the care that the sibling will receive in the future is the most common concern in both younger and older siblings with OS14 even stating that they are “constantly worried about what the future holds”. The reasons that the participants cite for this are multi-faceted and varied based on personal experience. Many express worries about what will happen to them and their sibling when their parents pass away, and the impact that this will have on their personal lives in the future. For example YS13 writes

“The task of ensuring high quality care will cause stress... to me and my other brother...what if we want to live abroad, would the carers dislike us for not visiting often enough?”.

This sentiment encapsulates the feelings that many of the other siblings seem to be expressing: they will have to care for their sibling but want to live an independent life too, a serious dilemma in their view.

The typical siblings also express concerns about what the best care option will be for their sibling in the future: themselves or outside care agencies. Several of the siblings explain that they are concerned for their sibling’s wellbeing in the future when they leave the care of their parents. For instance, YS6’s brother still lives with their parents and they state that as yet “no suitable other care has...been found” and YS1 says that “If something were to happen to my parents then it would be up to me... to care for my sibling with SEN”. These issues that may arise in the future appear to cause typical siblings significant stress regardless of birth order.

4.4.2 Funding
Concerns about funding are present in both older and younger sibling’s testimonies. Younger siblings were more concerned about funding issues than older siblings on average. The lack of adequate funding is clear from the stories of the participants. Participant YS10 states:

“Only within the last year he has been having showers again [sic], because of the lack of funding there was”

This illustrates the severe need for more substantial funding for adults with severe needs. The new Personal Independence Payment (PIP) scheme in the UK has a rigorous assessment process and the amount of funding that an adult receives is based on how much help they need in areas such as dressing, preparing food, eating and making decisions about money (Gov.uk, 2016). The new assessment scheme could be beneficial to some families, as it more accurately reflects their needs and allows them to access the proper funding to allow for the person with a disability to lead a more independent life. However, the participants mention that the cutbacks in services that their sibling attends or uses are detrimentally affecting their sibling’s independence. OS5 states that they are experiencing the effects that funding cuts are having on services, and as their sibling and parents are aging they are relying more heavily on day services and education placements which are getting removed. This situation leaves families in the difficult position of using their own, sometimes limited, funds to secure a place at a day service with proven benefits (Dabelko-Schoeny and King, 2010) or losing that place and impacting the wellbeing of the person with a disability.

4.4.3 Inadequate Care and Wellbeing

Both groups of typical siblings expressed concerns about the state of their sibling’s current care. Younger siblings were most worried about the issues surrounding their sibling’s current care (46% / 35%).

From the statements of the typical siblings it seems that the fight for adequate care in an out-of-home setting is arduous and stressful for the family for many reasons including the particular needs of the sibling. For instance OS7 recounts a time when the home that her sister is living in almost closed down several years ago:
“Trying to find somewhere else that was appropriate was terrible – she doesn’t fit into a lot of the boxes that are often catered to or referred to”

Other siblings share similar experiences of not being able to find adequate care for their sibling, where their specific and complex needs can be met. Literature shows that good care facilities for people with complex needs must be flexible and responsive to the individual, and allow them freedom of self-expression in order to provide the best possible experience (Muenchberger et al., 2012). This doesn’t appear to be common practice from the experiences of the typical siblings, as other typical siblings are stating that their sibling’s needs are not being met fully in their current care facilities. Improving the care facilities of people with complex and severe needs can promote a multitude of benefits for the individual such as independence which leads to raised self-esteem and confidence, ultimately leading to improved quality of life (Coleman et al, 2015).

Older siblings were more worried about the emotional wellbeing and independence of their sibling than younger siblings (86% / 53%). Their concerns centre on their sibling not being able to live a ‘normal’ life in which they can live in their own home or take part in activities which they enjoy without help. The topic of wellbeing and independence is clearly linked to both inadequate funding and inadequate care within the sibling’s statements. This is evidenced in OS8’s description of her sibling’s current situation in which her brother’s emotional wellbeing and independence are no longer a priority due to the more pressing issue of meeting his basic needs in a dignified and timely manner which is not happening in his current care facility. The independence of a person with severe and profound needs can be supported in a variety of ways, and it is a vital aspect of living a fulfilling life (Ayres et al, 2013). By helping the individual with a disability the family as a whole, including siblings, is being aided as the stress and confusion that is attached to caregiving and finding appropriate care is reduced.

4.4.4 No Concerns

The participant, YS8, who stated that they had ‘no concerns’ appears to be an anomaly in this study but explains their choice by stating:
“He is a much happier person now that he is older. He lives in a care home that he likes very much and he is well-supported. He lived with our parents for a long time, but he has a much better life now- it is more person-centred and responsive to his needs”

This participant provides an interesting view of the typical sibling experience as they do not seem to feel the responsibility of care that most of the other siblings seemed to feel despite growing up with the idea that they would one day be their sibling’s sole caregiver. They say:

“My parents always told me that I would have to look after my brother when I grew up. That was really frightening for me when I was a child. I will always make sure that he is ok. I will fight for him to have what he needs. However I do not feel responsible for him. We grew up and we are adults. We have our own lives and that is fine.”

It is not clear what has influenced this participant’s thinking or what variables have shaped their views to be so drastically different to the other participants. However, this account provides a valuable, interesting and unique look into the views of a typical sibling who does not seem to have been affected by the societal expectation of familial care.
Chapter 5 – Conclusion

At the outset of this research project it was intended that the experiences of typical siblings would be examined, and the effect of birth order on aspects of the sibling’s life would be explored. A significant difference in most or all areas was expected. In actuality, there was only a small difference in the experiences of the older and younger siblings in most of the themes that were extracted from the data. In summary, the findings were that older siblings rated their sibling relationship more highly than younger siblings, rated their social life as being more strongly affected by their sibling than younger siblings and had more concerns about their sibling and themselves than the younger siblings.

The value of this study could be considered limited due to the relatively small sample size compared to other studies involving typical sibling/sibling with SEN/D dyads and the lack of direct influence that this topic has on any particular profession or setting. However, a deeper understanding of the typical sibling experience has the potential to be useful in a range of settings and exploring the variable of birth order provides an added perspective to the already fascinating literature on family and disability. By exploring the views of siblings, an often forgotten aspect of family life for those with a disability, the family unit can be considered more holistically.

Despite the research the reasons for why there is a difference in the views of older and younger siblings remains largely unexplored in the literature. Because of this further explorative research into why the trends found in this study emerged could provide a depth to the findings. Further research would be interesting as although trends in the experience of siblings were correlated with birth order, the reasons for the trends could not be fully explored due to time constraints. Understanding why aspects of sibling experience, such as sibling relationships and concerns, were slightly differentiated between older and younger siblings would be interesting and add further depth to the knowledge base around the unique and personal experience of the families of individuals with disabilities. Furthermore, some aspects of the study would benefit from clarification or further qualitative examination, specifically the ‘social life’ and ‘family life’ components of the questionnaire as the siblings
were only asked to rate how strongly affected each aspect of the social or family life was by their sibling with SLD/PMLD, and it was not determined if these aspects were affected positively or negatively. It has been assumed for the purpose of this report that the siblings were affected negatively but further research into this area would clarify the issue and represent the experiences of siblings more realistically and fully.

Overall, the study holds some value in exploring the experiences of siblings with SLD/PMLD and exploring the role of birth order in the highly complex and individual experience of siblings. Although this study has been interesting, no overarching conclusions can be drawn from this study due to the nature of the topic, in which each individual is likely to have entirely different experiences and views of the same issues.
References:

Aldridge, J. and Becker, S. (1994). *A Friend Indeed; the Case for Befriending Young Carers.* Loughborough University; Young Carers Research Group.


Beresford, B. (1994). ‘Support from services’ in Positively Parents; Caring for a Disabled Child. London: HSMO.


Appendix One – Consent letter prefacing online questionnaire.

Please DO NOT complete this questionnaire if you are UNDER 16 years of age or live OUTSIDE THE UK (England, Ireland, Scotland, Wales)

My name is Annabel Cook, a third year Ba Special Educational Needs and Inclusion student at the University of Northampton.

The purpose of this research is to find out your personal experiences of having a sibling with special educational needs or a disability. The information will be used in my dissertation research report and may be presented in an academic journal.

For the purpose of the research report you will be asked to provide a code which will allow for your answers to be identified should you wish to withdraw you information. I will take every measure to ensure that your rights to confidentiality are protected. I will destroy your data once the report is written however, due to the nature of data being shared online, even through an anonymous medium, I cannot guarantee that your data will be destroyed from Google’s databases. Until the data is destroyed it will be stored on my personal computer, not on any public devices or shared computers.

If you wish to withdraw from the study you may do so at any time before the 20th of March by informing me via email and quoting your unique code.

Please do try to answer the questions as honestly as possible and with as much information as you are willing to give but please do not hesitate to refrain from answering a question if you are uncomfortable with it.

If you wish to be debriefed on the findings of the research at the end of the study please contact me via e-mail after the 22nd of April.

By continuing with the questionnaire you are agreeing that you fully understand the above terms and that you are consenting to having your data used in this study.

Thank you for your participation.
Annabel Cook.

The University of Northampton
Appendix Two – An extract of the coded responses to illustrate how the data was analysed.

Government agendas and priorities - low priority of all people with disabilities Professionals have low expectations and lack expertise of this population

Who going to look after my sibling if any think happens to my parents or when they get older. Will it be down to me. Also what happens when she finished education? What help and support will she received, or will it be down to my parents and me.

My concerns are that she isn’t independent, and is easily persuaded into doing stuff. Her boyfriend has also got an SEN, and he takes advantage of how nice she is, which is my main concern.

I am worried as to what will happen when my parents are no longer with us and who will look after her. I do not know if she will ever move out into a place of her own.

As a professional in education I see the effect funding cuts have upon services and as my parents get older we will rely even more heavily on daily services and further education placements.

I’m worried about what will happen when my parents are too old to look after her. My other sister and myself are of very similar age to my sister with SLD, and we may also be unable to care for her one day. I worry about her emotional well-being when my parents pass on because she has no real understanding of death.

I’m concerned about her future, and maintaining her balance and home life. She lives with 3 other adults with SLD, who all require 24 hour support/care (2 of whom she has lived with since moving out of home over 20yrs ago) they are also her family now and they all live well together. The home they live in nearly closed a few years ago which was very stressful. Trying to find somewhere else that was appropriate was terrible - she doesn’t fit into a lot of the boxes that are often catered for or referred to.

I didn’t mean to tick most of above - but unfortunately I do worry about the above, quite a lot of the time. I feel that other professionals and the local authority do not always have his best interests in mind. Due to his such high needs, he is expensive, and so future accommodation is a constant battle with social services to ensure his health and well-being is supported. I never feel like his needs are truly being met - but however much you try you can’t keep checking. You feel like you should be doing more all the time. But it’s a case of picking your battles and prioritising what is the most important thing to raise. For example, last March he was admitted into hospital with aspiration pneumonia, so now the battle is making sure he’s receiving regular physio, early detection with his GP and his dysphagia is safely managed. But before this it was asking for him to engage in regular art and staff to regularly use his iPad with him to support communication - still issues to support his emotional well-being, but it’s unfortunately no longer a priority.

I worry primarily about Joshua’s well-being and independence and this has an impact on the whole family.

As she gets older what provision will be available for her asp with cutbacks and changes to funding. Being the person I am raised the way I was, I am an excessive worrier.

Funding and support is terrible, and I worry that this will limit his opportunities. I also worry about my role as a carer when I am older and my parents are no longer able to care for him.

I have not realised until doing this list how many concerns I have! I think the main thing I am worried about is what will happen to my brother in the future. It sounds depressing but when my
Appendix Three – Tables showing the Demographic Characteristics of the Participants.

**OLDER SIBLINGS**

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<th>CODE</th>
<th>GENDER</th>
<th>AGE</th>
<th>AGE OF SIB</th>
<th>OTHER SIBS</th>
<th>BIRTH ORDER</th>
<th>DO YOU LIVE WITH SIBLING WITH SEN/D?</th>
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**YOUNGER SIBLINGS**

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Appendix Four– Approved Ethics Form

School of Education- Research Ethics Approval Form

Name of Student: Annabel Cook

Course and Module Code: BA SENI Dissertation, SEN 4001

Proposed Research Aim: To explore the views and life experiences of sibling of people with severe learning difficulties or profound and multiple learning difficulties.

Number of participants (approximate) and nature of the participants (e.g. parents, children, adults, service providers): 20-30. Adult siblings of people with SLD/PMLD.

The research involves field work [X] (data collected in school or with/from people)

The research does not involve field work. [ ]

For research involving children, young people or vulnerable adults, a DBS check is in place and accepted by the organisation where research is being conducted [ ]

<table>
<thead>
<tr>
<th>Ethical Principle</th>
<th>Action</th>
<th>Copy attached</th>
<th>Explanatory note if copy not attached</th>
<th>Approved by dissertation supervisor (signature)</th>
<th>Date of approval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communicate the research aims and details to all participants</td>
<td>Consent letter</td>
<td>Yes</td>
<td></td>
<td>Prithvi</td>
<td>28/1/16</td>
</tr>
<tr>
<td>Obtain evidence of their permission</td>
<td>Consent letter (by continuing with the questionnaire they are giving their permission)</td>
<td>Yes</td>
<td></td>
<td>Prithvi</td>
<td>28/1/16</td>
</tr>
<tr>
<td>Inform participants of their right to withdraw in entirety or withdraw a part of their data.</td>
<td>Consent letter</td>
<td>Yes</td>
<td>Prithvi</td>
<td>28/1/16</td>
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<tr>
<td>Protect the interests of vulnerable participants</td>
<td>No children or vulnerable adults will be participating, as stated in the consent letter.</td>
<td>Yes</td>
<td>Prithvi</td>
<td>28/1/16</td>
<td></td>
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<tr>
<td>Inform participants about the storage and use of data</td>
<td>This information is contained in the consent letter.</td>
<td>Yes</td>
<td>Prithvi</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ensure confidentiality and anonymity</td>
<td>No names will be used, outlined in consent letter.</td>
<td>Yes</td>
<td>Prithvi</td>
<td>28/1/16</td>
<td></td>
</tr>
<tr>
<td>Share research outcomes with participants</td>
<td>Participants can contact me after the research is complete to request the report. Communicated in consent letter</td>
<td>Yes</td>
<td>Prithvi</td>
<td>28/1/16</td>
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</table>

**Name of the student...** Annabel Cook

**Signature** A.Cook  
**Date** 26/01/2016
Record of Supervision.

<table>
<thead>
<tr>
<th>Student’s ID:</th>
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<tbody>
<tr>
<td>Name of Supervisor:</td>
</tr>
<tr>
<td>Student’s Programme of Study: Ba SEN and Inclusion</td>
</tr>
<tr>
<td>Research Topic: The views of siblings who have a brother or sister with SEN/D.</td>
</tr>
<tr>
<td>Date: 26\textsuperscript{th} Oct 2015</td>
</tr>
<tr>
<td>Nature of supervision: face-to-face</td>
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**Main focus of the discussion:**

1) How I can focus my topic to either concentrate on one specific disability or collect data on a wide range of disabilities through using a questionnaire and analyse the results accordingly.

2) How I could use literature to justify my choice for using older siblings specifically e.g. find journal articles that specifically compare older and younger siblings (and if this is not possible to expand my participants to include any birth order and adjust my research questions accordingly)

3) That I need to decide which variables I am focussing on and how I can control them.

**Actions:**

I will decide on an appropriate focus, most likely narrowing my sample to siblings (any birth order) of children/people with PMLD or SLD so that I can compare younger and older sibling views. (other variables such as gender and socio-economic status of the participants will be accounted for by using a mixed sample and discussing this in my final report)

I will continue my reading to further inform my choices and have completed my first draft of my literature review by the 30\textsuperscript{th} of November.

I will decide how big a sample size I want and decide if a case study or survey methodology would be more appropriate.

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<tr>
<th>Student’s signature</th>
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<tr>
<td>A. Cook</td>
<td></td>
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</table>
### First Meeting 19th Nov 2015

**Student’s ID:**

Name of Supervisor:

**Student’s Programme of Study:** Ba SEN and Inclusion

**Research Topic:** The views of siblings who have a brother or sister with SEN/D.

**Date:** 19th Nov 2015  
**Duration:** 30 mins

**Nature of supervision:** face-to-face

**Main focus of the discussion:**

1. How my literature review was coming along. Conclusion: It needs some revision but it is along the right lines.
2. The methods I will use. Conclusion: Questionnaires, with the possibility to use interviews before or after to gain more in depth information.

**Actions:**

I will continue with my literature review and submit it on the 30th of November.

I will start my Methodology and ethics and have these prepared by the end of term.

I will collate a list of the places I could send the questionnaire to.

**Student’s signature:** A. Cook  
**Supervisor’s signature:**

### Second Meeting 17th Dec 2015

**Student’s ID:**

Name of Supervisor:

**Student’s Programme of Study:** Ba SEN and Inclusion

**Research Topic:** The views of siblings who have a brother or sister with PMLD/SLD

**Date:** 17/12/2015  
**Duration:** 45 mins

**Nature of supervision:** face-to-face

**Main focus of the discussion:**

The first draft of my methodology was reviewed, and guidance was given about the method of sampling and the validity and reliability sections.

**Actions:**

I will change my methodology accordingly, and research further trustworthiness in relation to interpretivist and validity.

I will prepare my questionnaire to submit by the 20th of January.
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<tbody>
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<td><strong>Student’s Programme of Study:</strong> Ba SEN and Inclusion</td>
</tr>
<tr>
<td><strong>Research Topic:</strong> The views of siblings who have a brother or sister with PMLD/SLD</td>
</tr>
<tr>
<td><strong>Date:</strong> 03/03/16</td>
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<tr>
<td><strong>Nature of supervision:</strong> face-to-face</td>
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<tr>
<td><strong>Main focus of the discussion:</strong></td>
</tr>
<tr>
<td>Looking at the data collected and planning my next steps.</td>
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<td><strong>Actions:</strong></td>
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<tr>
<td>Condense the data and tidy it into excel sheets.</td>
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<tr>
<td>Send these to Prithvi when they are completed.</td>
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<tr>
<td>Look at what themes are emerging from the open questions.</td>
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<tr>
<td>Look at the differences in younger and older siblings in relation to my research questions.</td>
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| **Student’s signature** | A.Cook | **Supervisor’s signature** |