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# Futures planning, parental expectations and sibling concern for people who have a learning disability

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**Title: Futures planning, parental expectation and sibling concern for people who have a learning disability.**

**Abstract:**

The aim of this questionnaire was to explore the existence of future plans, parental expectation and sibling concern regarding people who have a learning disability.  A questionnaire was sent via email to siblings of people who have a learning disability.  21 completed questionnaires were returned and responses were anaylsed using descriptive statistics and thematic analysis.

A full discussion regarding sibling support was reported to have taken place by 12 (57%) of respondents, 7 (33%) stated this discussion had not taken place and 2 (9%) were unsure.  12 (57%) of participants reported no clear future plan however where a plan did exist, 7 (33%) of respondents claimed it was fully agreeable to both them and their parents.  11 (52%) of respondents reported no difference between their wishes regarding their future role and parental wishes.  Key themes generated were; satisfaction with services, parental influence, sibling concern about the future, futures planning, the impact of the disabled person upon sibling lives and siblings needs.

Further qualitative exploration into the personal wishes, reality and parental expectations for future support of siblings of adults who have a learning disability is required.

**Keywords:** adult siblings, futures planning, learning disability, parental expectation

**Abstract word count 186**

**Introduction**

People who have a learning disability are living longer than at previous times and many may have profound and severe disabilities.  This group of people often live with a parent well into adulthood (Emerson and Hatton, 2008) and even when learning disabled adults move away from the parental home, responsibility often remains within the family with siblings commonly viewed as next of kin when older parents die or are no longer able to provide previous levels of support.  The government acknowledged the importance of family members in the care of learning disabled people within the latest White Paper on learning disabilities (DoH, 2008) and a recent Commission for Social Care Inspection report found that many Local Authorities did not have sufficient futures plans in place  for the many learning disabled people who live with older parents (CSCI, 2006).  Despite this situation, there is a significant lack of empirical information related to the views, plans and wishes of siblings of learning disabled adults.

**Background**

Sibling relationships are often considered to be those that are the most enduring over the life cycle (Voorpostel and Blieszner 2008) and have particular relevance where one sibling within a family has a learning disability. Although this study relates specifically to the adult siblings of people who have a learning disability, it is important to acknowledge the findings of sibling research during childhood.  Earlier literature reviews of empirical studies such as the meta-analysis by Rossiter and Sharpe (2001) found a statistically significant but small negative effect on the psychological functioning of siblings of  learning disabled children which was identified as depression and to a lesser extent anxiety, internalising and externalising behaviours.  These findings are however in contract with later reviews by Stoneman ( 2005) and Meadan et al (2010) where results are much more mixed and in fact present some positive aspects to be gained such as enhanced maturity and understanding of the needs of disabled people, although it may be true that the experience of growing up with a disabled sibling is negative for some children. Research into the value of support groups for children who have a learning disabled brother or sister indicates increased levels of sibling interaction, self esteem and knowledge of learning disability by participation in such groups and may have implications for levels of support and engagement in later life (Evans et al 2001).

Within our society, there is often an expectation that siblings will take over when older parents are no longer able to provide previous levels of support and  older parents themselves may

have an expectation that siblings will provide some level of support in their absence (Davys and Haigh 2008).   The significance of family carers is now acknowledged within the political context (DoH 2008) and a review of the literature in this field demonstrates a varied impact upon sibling lives in areas such as their experience of growing up within the family (Cleveland and Miller 1977), life choices related to career, friendships and marriage partner, personality and well being  (Taylor 2008) future plans and identity (Flaton 2006).  In a similar way, sibling roles and relationships centred around learning disability are varied, ranging from those that are very warm and involved, to those that are distant and disengaged (Zetlin 1986).   Roles undertaken by siblings are also varied and include financial manager, social support, companion and decision maker (Bigby 1997), however these roles are often linked to the life and transition stage of the individuals involved.  The nature and characteristics of these roles and relationships changes over time (Kramer 2008), often diverging as siblings grow up and establish independent lives away from the family home and later converging as siblings age (Jokenin 2008).

Factors within the literature that are seen to impact upon the involvement of siblings with learning disabled brothers and sisters include gender, age,   birth order (Richardson 2009) and family climate.  Such evidence is inconclusive according to Rimmerman and Raife (2001) yet significant in reference to Greenberg et al (1999).  Parental expectations of care giving and involvement (Zetlin 1986, Greenberg et al 1999) are also reported to have an effect upon sibling involvement.  Empirical research states that siblings of learning disabled people are concerned about the future and in particular feel a sense of responsibility for the time when parents will no longer be able to provide support (Orsmond and Seltzer 2007) with many holding expectations of greater care giving and commitment in the future (Greenberg et al 1999 ).

In addition to their concerns for the future, siblings in this situation also have needs and wishes of their own.  Benderix and Sivberg ( 2007) advise early intervention programmes and proactive futures planning that meet the needs of individual families and their members, along with counselling services for parents and siblings, either individually or as a group.   It is also suggested that siblings have access to peer support groups.  As many sibling state that they want   to be involved in the lives of their disabled brother or sister, the need for information on

services, support with futures planning, financial issues, leisure and residential opportunities, as well as the opportunity to develop support networks which include internet groups  are also highlighted (Heller and Kramer 2009 ).

The aim of this survey was to investigate adult siblings of people who have a learning disability in relation to demographic details, the existence of plans for the future, parental expectation and concern about future care.  The results of the questionnaire will then present sibling views on this topic and will be used at a later date to inform deeper exploration of this phenomenon within a qualitative study.

This therefore  is a significant area for research as the literature surrounding adult siblings of people who have a learning disability suggests that  many siblings are concerned about the future and although many are willing to assume  supportive roles, in many instances they do not expect to take on the role of surrogate parent (Bigby 1997,Zetlin 1986) .  As siblings move through the life cycle from childhood through to older adulthood, consideration of their needs, wishes and ability to take on a supportive role needs to be addressed (Benderix and Sivberg 2007).  It  is important therefore that those working in the field of learning disabilities have an understanding of the issues and factors that are likely to shape and impact upon the care giving relationship and that due support be provided to siblings.

**Methodology**

Before any part of this research study was undertaken, ethical clearance was sought and granted from the university ethics committee and by Sibs, the UK charitable organisation for people who grow up with a disabled brother or sister.

The questionnaire (appendix A) was sent out by email via the Sibs organisation who passed the questionnaire onto 200 people on their database.  Any person who is an adult sibling to a person with a learning disability aged 25 or over was invited to take part.   An initial invitation and a follow up invitation to take part was sent out, data was collated between November 2009 and January 2010.  In total, 21 respondents returned the questionnaire .

The questionnaire was constructed following a literature review of empirical studies related to the adult siblings of people who have a learning disability  and sought to gain information on basic  background demographic data, the existence and degree of parent / sibling agreement around futures planning and sibling concerns about the future.   The questionnaire

predominantly contained closed questions with one open section at the end.  Self – reports can be utilised within social research and approached using an open interview situation or by a more closed questionnaire as both form a means of self-report in relation to a specific phenomena and so can be viewed as different tools along the continuum of self report (Polit  et al. 2001).

Participants self-selected by choosing to complete and return the questionnaire as found in appendix A which was sent out via the Sibs organization and requested information on demographic details, the existence of futures plans, the degree to which futures plans are agreeable to both parents and siblings, any difference between parental and sibling wishes related to futures  planning, whether or not siblings are concerned about the future impact of the disabled sibling upon their own lives and finally an open section where participants were invited to note any other thoughts or comment.

Descriptive statistics in the form of percentages are presented for the closed questions.  A form of content analysis was used to analyse the written comments made by 14 respondents (67%). The procedure used to analyse the written comments was as follows; each comment was read through and key  issues arising were underlined, a  note of each respondent by number was made and key sentences were written down in a comment box against the number of each respondent e.g. "problems with housing" or "I feel guilty that I am able to have a normal life compared to that of my sibling".  After each comment box was reviewed and key sentences for all respondents noted, commonality of theme was sought and key themes noted, some of which were then incorporated into other broader themes.


**Results**

In total, 21 participants returned questionnaires.  The small number of respondents is noted and therefore the results presented should be considered as an indication of adult sibling views and may differ from results generated from a large scale research study.   The majority of participants (18, 85%) were women, and 16 (76%) were under the age of 45.  4 (19%) were in the 45-54 year old age range and 1 (4.7%) did not state their age.


With regard to geographical location, the majority (9 , 42%) of participants lived in the South East of England, 4 (19%) came from the North West, 3 (14%) each came from the North East

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and the Midlands whilst 2 (9%) came from the South West. In terms of living situation 9 respondents (42%) lived with a partner, 5 (23%) lived with a partner and children, 6 (28%) lived alone and 1 (4%) lived with parents. No participants lived with their parents and a disabled sibling. All participants reported some level of contact with the disabled sibling (table 1). The most commonly stated level of contact was more than once per week (5 , 23%), 4 participants (19%) reported contact as couple of times a month and 3 participants (14.2%) each stated that they had contact once a week, once every three months and once every six months.

| Table 1 Sibling level of contact with the disabled person | |
|---|---|
| **Level of contact** | **Number of respondents** |
| More than once per week | 5 (23%) |
| Once per week | 3 (14%) |
| A couple of times per month | 4 (19%) |
| Once per month | 3 (14%) |
| Once every 3 months | 3 (14%) |
| Once every 6 months | 3 (14%) |

The results of questions related to future role , futures plans and parental expectation ( questions 6-9 of the questionnaire) are charted in table 2.  This table shows that over half  the participants reported a full discussion between themselves and their parents regarding future support for  the person  with a learning disability had taken place although this was not the case for almost 1/3 rd of respondents.  Over half the number of participants stated that there was no clear futures plan in place and where a plan did exist, this was fully agreeable to almost 1/3rd of participants.  Slightly over half the respondents stated no difference between their wishes and those of their parents regarding a future care giving role.

**Table 2 Responses to questions 6-9 of the questionnaire**

| Question | Respondent answers | | |
|---|---|---|---|
| | Yes | No | Unsure |
| Has there been a full discussion between siblings and parents regarding future support role ? | 12 (57.1%) | 7 (33.3%) | 2 (9.5%) |
| Does a clear futures plan exist? | 9 (42.8%) | 12 (57.1%) | 0 |
| Where a plan exists is it fully agreeable to parents and siblings? | 7 (33.3%) | 1 (4.7%) | 5 (23.8%) |
| Is there any difference between sibling wishes and those of parents regarding future role for disabled person? | 7 (33.3%) | 11 (52.3%) | 3 (14.2%) |

**NB. 8 respondents (30.0%) did not answer question 8 of the questionnaire possibly as the previous question asks if there is a clear plan and 11 (52%) of respondents stated that there was not a clear plan**

The majority of respondents (14, 66.%) stated that they were concerned about the effect supporting a disabled sibling may have upon their own lives in the future. 4 (19%) were not concerned and 2 (9.5%) were unsure. 1 respondent marked both the yes and no boxes, the yes box was marked with the comment "It has already affected my career" and the no box was marked with the comment "I don`t think about it".

The relationships between respondent and disabled sibling ( question 11) were reported to be that of full brother / sister in the case of 19 (95.%) respondents and half brother / sister for 1 (4.%) respondent. All respondents stated that their mothers were alive, 16 (76%) reported their father was alive, 12 (57%) that both mother and father were alive, 5 (23%)reported mother only alive, 2 (9%) reported mother, father and step father alive and 1 (4%) stated mother, father and step mother alive. 1 respondent (4.7%) noted that father was alive but not in touch with the disabled person.

## Discussion

In total 21 respondents returned a completed questionnaire. The majority of respondents (9, 42%) were in the 25-34 years of age category and none were over 54 which may mean that as the questionnaire was sent out by email, it is younger rather than older siblings who had access to the questionnaire. The living situation most common was of a sibling living with a partner (9, 42%) and the most commonly reported level of contact (5, 23%) with the disabled sibling was more than once a week. 20 (95%) of respondents reported that their relationship with the disabled sibling was that of full brother / sister and 1 (4%) stated it was that of half brother / sister with no step or adoptive relationships represented. 21 (100%) of all participants mothers were alive, 16 (76%) of fathers were still alive and for 12 respondents (57%) both mother and father were alive. The fact that all mothers are still alive may have an impact upon the results as care arrangements may change after maternal death, especially if the mother is the last surviving parent.

12 respondents ( 57%) stated that there had been full discussions with their parents regarding their future support role for the disabled sibling, however 12 (57%) also stated that there is no clear futures plan currently in place which would suggest that although parents and non-disabled adult children may discuss the type of support they could provide when parents are no longer able to do so, this does not necessarily translate into a formalised futures plan. Where a plan did exist, 7 (33%) respondents stated that it was fully agreeable to both them and their parents, 1 participant stated that it was not fully agreeable and a further 5 respondents (23%) claimed that they were unsure if the plan was fully agreeable to both parties. The most likely reason for this was that the previous question asks if there is a clear plan for future support and 11 (52%) respondents stated that there was no clear plan which would make this question difficult for them to answer. When asked about any difference between their own ideal wishes regarding their future care role and that of their parents, 11 respondents (52%) claimed that there was no difference, whilst 7 (33%) felt that there was a difference and 13 (4%) were unsure about any difference. The majority of respondents (66%) stated that they were concerned about the future effect supporting a disabled sibling may have upon their lives in the future.

**Written comments:**

**1)Satisfaction with services**

This was the most commonly occurring theme. Comments under this theme include dissatisfaction with services, satisfaction with services, not wanting the learning disabled person to go into care, and the family having to take control when services are not up to standard. In total 15 comments that relate to the categories stated above were made.

11 negative comments were made by siblings about services. The lack of housing and the number or type of options siblings consider to be appropriate is noted. Services are said to be of an unacceptable / inappropriate standard, they are reportedly lacking in their ability to understand the needs of people with a learning disability and their families, and emergency care arrangements are said to be inadequate. Within this theme is encompassed the comment that respondents do not want their learning disabled siblings to go into a care home and that when services are not appropriate or break down, responsibility for care falls back onto the family, both of which can be interpreted as negative comments. Parental dissatisfaction with services is a common theme within the literature related to learning disabilities as evidenced by

Davys and Haigh(2008) and this negative view of services now appears to be shared by the sibling respondents within this study. It is important to note however that not all siblings held a negative view of services, 3 positive comments were made that included the learning disabled person being settled in a residential care setting although it had taken a long time to find the right type of care and a few settings had been tried before the right one was located.

**2)Parental influence / impact on the issue of futures planning and care situation**

A total of 10 comments were made making this the second most commonly occurring theme. The question of parental influence upon futures planning and the care situation presents a mixed picture. Some siblings respondents note frank and open discussion e.g. Respondent 7 states that the family openly discuss options about future care and that parents want to avoid the person with a learning disability living with their sibling as this would be viewed by parents as an impediment to the lives of both parties, a comment that is reiterated by respondent 3. Respondent 10 feels that parents have expectations of greater involvement from them with their disabled sibling in the future, although there is no significant negative comment attached to this statement. In contrast to this however, issues of significant concern and distress are apparent; Respondent 4 claims that discussing future care with parents is a major problem and parental distress at the topic of futures planning is upheld by Respondent 6 who claims that parents "bury their heads in the sand" which leads to much frustration as parental refusal to discuss the situation means that future care for the person with a learning disability is unresolved.

The view that parents wish to avoid placing perceived burden upon the non-disabled siblings as they are considered by parents to have their own lives and have already been affected by the family situation is supported by Davys and Haigh (2008). Within this study it was found that parents report a joint expectation for non-disabled children to develop their own independent lives yet at the same time the expectation is that they will have future involvement in the lives of the disabled person. The link found within this study between sibling involvement and parental expectation is supported within the literature by both Zetlin (1986) and Bigby (1997) and the presence of stress for parents in discussing future plans for their learning disabled off spring is also supported by studies such as those by Knox and Bigby (2007) who report that discussing

futures plans with parents is a highly sensitive topic and that by Gilbert et al (2008) who found that parents were reluctant to make and discuss plans for the future.

**3) Siblings are worried about the future, Futures planning issues and Impact of learning disabled person upon the sibling life**

Each of these themes gained eight  comments making this the third most commonly occurring theme.  Respondents within this study reported different worries regarding the future and their role in supporting the person with a learning disability. These worries included the support needs of the disabled sibling as they age, concern about future responsibilities and how they will have to prioritise the needs of the disabled sibling against those of their own families. Respondent 9  states that she has recently married and hopes to have children in the future, yet for her this situation will bring "immense pressure" as the disabled  sibling will have to come second on the priority list.   Respondent 20 comments that they are very worried about the future when parents are not here to provide care as the disabled  sibling already has a "massive" effect upon his own life and that of his entire family.  Prior  empirical studies reiterate sibling concern about the future, especially when parents are no longer able to provide  support. Studies by Orsmond and Seltzer (2007) and  Benderix and Sivberg (2007) equally found siblings to be concerned or pessimistic about the future for their disabled brothers or sisters and the  view that siblings actually take on parental fear regarding the future and what will happen to their disabled sibling when they are no longer here to oversee care is presented by both Kramer (2008) and Karasik (1993).


From the results of the questionnaires, only in one case ( Respondent 7) is futures planning said to be openly discussed within the family.  Other respondents report that their involvement in futures planning is limited to financial input such as the respondent  holding money in trust for the disabled  sibling.  Respondent 5 claims that futures planning is a difficult process that impacts on both the disabled person and the family at large, and a lack of services and choice makes the process difficult.  Again the results of this study are supported by previous research by Heller and Kramer (2009) who found that only one third of the families in their study has made future residential plans, the types of plans made often related to guardianship or financial arrangements and one third again had identified a future care giver.  The lack of appropriate

services has been previously highlighted by Bowey et al (2005) who note the difficulties parents encounter in the emotional "letting go" of their disabled child in addition to the service issues.

When asked about the impact that a learning disabled sibling may have upon an individual's life, responses generally present the view that an extra care role and that of "overseer" to make sure that the needs of the LD person are met when parents are no longer able to provide this role is expected.  An example of this is found in the comment made by respondent 8 where  the respondent had  "promised"  parents that they will "always make sure that he is well looked after".  This theme also incorporates the concept that current / future partners will have to accept the disabled sibling and accommodate them so some extent.   Previous research indicates that having a learning disabled sibling does affect sibling lives in areas such as career choice, partner choice, decision to have children, plans for the future  and feelings about people who have a disability (Seltzer et al 1997) and the expectation to take on a care or "overseer" role is reiterated by Bigby (2007) and Rigney (2009)

**4) Siblings have needs**

This theme gained  five  comments in total  and so was the least commonly occurring theme. By analysing the results of the questionnaire, it is clear that respondents felt the need to communicate  their point of view, to be informed of available options and involved in futures planning.  Participants noted  that better quality and a wider range of accommodation options needs to be available and that there is a lack of support for people in their situation.  These findings are again supported by previous research such as that  by   Benderix and Sivberg (2007) who found that as siblings move through the life cycle from childhood through to older adulthood, consideration of their needs, wishes and ability to take on a supportive role needs to be addressed.  Early intervention programmes and proactive futures planning that meets the needs of individual families and their members is called for by siblings themselves along with counselling services, peer support groups, information on services and futures planning, financial issues, leisure and residential opportunities so as to support siblings to be effectively involved in the lives of their disabled brother or sister (Heller and Kramer 2009 ).

**Limitations**

The majority ( 18, 85.%) of participants were women who self-selected their involvement in this study and matters of ethnicity, education or socio-economic status were not addressed. It is also accepted that the questionnaire captures only those individuals known to the Sibs organisation and who have access to the internet and email system.  No one over the age of 54 took part in the study, the majority of respondents (9, 42%) lived  in the South East of England, and there were no sibling responses from Scotland, Wales or Ireland. The organisational database to which the questionnaires were emailed holds approximately  200 contact details however as a total of only 21 replies were received, a response rate of 10% is clearly low, raising issues of bias and generalisability (Robson 2002).  Despite this, a low response rate needs to be considered carefully and not quickly dismissed as none representative of a population but rather set within a given context.  It is important to acknowledge that the questions may be deemed sensitive as they refer to issues that are private and personal (Oriell and Dudley 2009) and sensitive questions are commonly found to have a low response rate.  With particular reference to the response rate, and links with generalisability within research studies, Keegan and Lucas (2005) make the point that there is an unhealthy significance attached to high response rates which in turn may create bias and lead to an important area of knowledge being either ignored or under-represented.

**Areas for further research**

 Despite this being a small scale study, the results and context support further investigation of the topic.  Some siblings raise the issue of futures planning and parental impact upon this situation to be a major concern and difficulty for them and their own families, whilst others report a more settled situation.  Such evidence of diversity within different contexts is in itself worthy of further investigation.  The low response rate may be linked to the view that this is a sensitive area for people that needs careful exploration so that concerns are raised and developments made rather than issues being ignored and marginalised.  In addition to these considerations, there is a lack of empirical research in this area (Hodapp and Urbano 2007) despite government  awareness and acknowledgment of the role of family carers and lack of futures planning for learning disabled people (DoH 2008, CSI, 2006).

**Conclusion**

Within the context of this small scale research study the findings clearly show that  although all respondents had contact with the disabled person at least once every six month, just over half

state that there has been a full discussion with parents about their future role with  the same number also stating that there is no clear formalised futures plan in place.  Even where a future plan does exist, only a third of siblings were able to say that the plan was fully agreeable to both parties.  As such, there appears to be a lack of clarity between siblings and parents in relation to futures plans for people who have a learning disability.  Just over half the respondents felt that there was no difference between their personal wishes and those of their parents for  a future support role  yet three quarters of participants were concerned about the impact supporting a learning disabled sibling would have on their own future lives, which suggests that this is an area of concern and anxiety.

The written comments made within this study present diversity within the sibling experience.  Satisfaction with services is a significant issue generally within learning disability services and the majority of respondents who commented on this theme were dissatisfied, reporting that services are not of an appropriate standard, and lack understanding of the needs of families in this situation.  Some siblings did however report satisfaction with residential care but noted that it can take families a long time to find a setting which they feel is appropriate.  The influence of parents upon the futures planning process presents a mixed response, some siblings report open and frank discussion within the family whilst others claim that parents are unable to discuss the future which can be a cause of great frustration and distress.  A third of the respondents within this study raised concerns about the future, futures planning and the impact of the learning disabled person upon their lives.  Such worries include what will happen when parents are no longer able to provide current levels of care and how siblings will manage and prioritise care of the disabled sibling alongside responsibilities to their own families.

Sibling involvement in futures planning appears to be limited to areas such as financial management by parents for some, and the planning and financial constraints of social service departments for others.  Participants who commented under this theme did however present as having an expectation to take on extra care responsibilities and act as "overseer" when parents are no longer able to provide previous levels of support.  The final theme raised within the written comments was that siblings of learning disabled people have needs of their own that include having their voices heard and access to support. Siblings want assistance in being able to provide appropriate support to their learning disabled brothers and sisters that includes futures planning and having access to better quality and a greater range of services. As the

majority of respondents were concerned about the future impact of a learning disabled siblings upon their own lives, the diversity of response, lack of empirical research and sensitivity of the topic, strongly indicates the need for further qualitative research into this area.

**Word count 5020**

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**Appendix A:**

# Questionnaire for Adults aged 25 and over who have a brother or sister who has a learning disability – Concerns for the future

**There are twelve questions to complete and space for additional comments. Please place a cross (X) in the appropriate box and return the completed questionnaire to either the email or postal address given at the end.**

**1) How old were you on your last birthday?**

| |
|---|
| |

**2) Are you?**

| Male | |
|---|---|
| Female | |

**3) Where do you live?**

| Scotland | |
|---|---|
| North East England | |
| North West England | |
| Wales | |
| Midlands of England | |
| South East England | |
| South West England | |
| Ireland | |

**4) At the moment are you?**

| | |
|---|---|
| Living with parents | |
| Living with parents and learning disabled brother or sister | |
| Living with partner | |
| Living with partner and children | |
| Living with children | |
| Living alone | |

**5 )How often do you have face to face contact with your learning disabled brother or sister?**

| | |
|---|---|
| More than once a week | |
| Once a week | |
| A couple of times each month | |
| Once a month | |
| Once every three months | |
| Once every 6 months | |
| Once every 9 months | |
| Once a year | |
| No contact | |

**6) Has there been a full discussion with your parents about the support you might provide to your disabled brother / sister when they are no longer able to provide care?**

| | |
|---|---|
| Yes | |
| No | |
| Unsure | |

**7) Is there a clear plan for the future support of your learning disabled brother / sister?**

| | |
|---|---|
| Yes | |
| No | |
| Unsure | |

**8) If a plan exists, is it fully agreeable to both you and your parents?**

| | |
|---|---|
| Yes | |
| No | |
| Unsure | |

**9) Is there any difference between your ideal wishes and your parents' wishes with regard to your role in the future?**

| | |
|---|---|
| Yes | |
| No | |
| Unsure | |

**10) Do you feel concerned about how supporting your disabled brother / sister may affect your own life in the future?**

| | |
|---|---|
| Yes | |
| No | |
| Unsure | |

**11) Is your relationship with your learning disabled brother / sister that of:**

| | |
|---|---|
| Full brother / sister | |
| Half brother / sister | |
| Step brother / sister | |
| Adoptive brother/sister | |

**12) Are the following still alive?**

| | |
|---|---|
| Mother | |
| Stepmother | |
| Father | |
| Stepfather | |

**Having read through and answered this questionnaire, are there any thoughts or comments you would like to make. If so, please write them in the box below.**

```
                                                                    
                                                                    
                                                                    
                                                                    
                                                                    
                                                                    
                                                                    
                                                                    
```

**Thank you very much for your time and co-operation in completing this questionnaire.**

**\*If you feel that the questionnaire has raised any sibling issues you would like to discuss, Sibs is a UK organisation for siblings of disabled people and they can be contacted by telephone on 01535 645453, Email info@sibs.org.uk  Website www.sibs.org.uk**