Parents’ Views on the Social Well-Being of their Child with Learning Disabilities

by

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Adult Mental Health Essay

"The involvement of consumers is more likely to produce results that can be used to improve practice" (DoH, 2000). Critically discuss this statement and any implications for the role of the Clinical Psychologist.

January 2004
Year 1
The nature of healthcare provision has changed dramatically since the National Health Service (NHS) was first established. Previously patients were more likely to suffer from acute and life-threatening illnesses, which meant the rationale for treatment was often relatively straightforward. Doctors took a paternalistic approach to patient care, rarely offering an explanation for their choice of diagnosis or treatment, and patients believed their doctors knew best and trusted they were acting in their best interests. Today however, patients are more likely to suffer from chronic conditions, which are not necessarily life-threatening but which have a long course. This and the fact that there are many more treatment options makes the rationale for treatment much more complex (Dunning & Needham, 1994). In addition the media's criticism of the NHS has had profound consequences on the public's perception of healthcare professionals. They are no longer viewed as infallible and unquestionable 'experts'. The result is a society that demands information and participation in the decision-making processes involved in healthcare provision (Dunning & Needham, 1994).

The government has embraced this movement and encourages the perception of service users as "owners" of the NHS. Not only is this a political imperative (Telford, Beverley, Cooper and Boote, 2002), given the way the NHS is funded, it is also a good way of moving away from the culture of blame that has blighted the NHS (and the department of health) in recent years.

In 1996 the government took the movement one step further and encouraged service users or 'consumers' to become involved in health related research. The Standing Advisory Group on Consumer Involvement in the NHS Research & Development programme was established with aims to ensure that consumer involvement in NHS R&D improves the way research is prioritised, commissioned, undertaken and disseminated. The group states that the involvement of consumers in research "is more likely to produce results that can be used to improve practice." (NHS Executive, 2000). Surprisingly this statement, made by a group that exists for the NHS R&D programme, has no basis in research (Chalmers, 1995; Buckland & Gorin, 2001).

There is no evidence for it. There seems to be an assumption that consumers

1 The Standing Advisory Group on Consumer Involvement in the NHS R&D programme is now known as Consumers in NHS Research.
somehow hold the key to improving practice and another that their involvement will improve or at least not hinder the research process. Surely this depends on what is meant by improved practice and how the research process is adapted to involve consumers?

In the following essay we shall discuss the ways in which consumer involvement in NHS R&D might lead to improved practice in terms of consumer satisfaction, improved research quality and improved implementation of research findings. We shall then examine the limitations of consumer involvement in NHS R&D described by professionals. These include issues of representation, understanding, realism, time, money and power. This will lead us to examine consumer responses to the professionals’ comments. Finally, we shall describe some of the implications of this statement for the role of the Clinical Psychologist as a clinician and a researcher.

1 Who are Consumers and what is Consumer Involvement?

In this essay we have already used the terms ‘patients’, ‘service users’ and ‘consumers’ and although it is recognised that all three have distinct meanings and connotations we are using them interchangeably for ease of expression.

If we are to critically discuss the Consumers in NHS Research statement it seems necessary to understand what they mean by ‘consumer’ and ‘consumer involvement’. Consumers in NHS Research define ‘consumers’ as “patients, carers, long term users of services, organisations representing consumers’ interests, members of the public who are the potential recipients of health promotion programmes and groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services.” They recognise that we are all potential consumers of National Health services but suggest that consumers who become involved in R&D and do not have other ‘professional’ roles have a “distinct and complementary role to play in the R&D process.” (NHS Executive, 2000)

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2 Research and Development will be referred to as R&D from now on.
Consumers in NHS Research go on to define ‘consumer involvement’ in R&D as “an active partnership between consumers and researchers in the research process, rather than the use of consumers as the ‘subjects’ of research.” They suggest that consumers should be involved at every stage of the research process. In other words, they should be involved in prioritising NHS research agendas (Royle & Oliver, 2001), setting research questions, designing research projects, conducting research projects, and interpreting and disseminating research results (Hanely, Truesdale, King, Elbourne and Chalmers, 2001).

2 What are the Benefits of Consumer Involvement?

2.1 Consumer Satisfaction as a result of Consumer Involvement

By recognising consumers as ‘owners’ of the NHS and therefore as a group to which it is ultimately accountable, the government has also recognised the importance of consumer satisfaction. Does the statement made by Consumers in NHS Research imply that good practice is defined by consumer satisfaction? If this is the case how will consumer involvement in NHS research improve consumer satisfaction?

Evidence suggests that there are important mismatches between the priorities of professionals, researchers and consumers. Consumer priorities include long term health needs, the impact of disability on quality of life for individuals and their families and the provision of information. On the other hand researcher priorities include areas that developed new frontiers of knowledge and professional priorities include areas that promote professional interest (NHS Executive, 1999). As a result consumer involvement in R&D could promote consumer satisfaction if it allowed consumer priorities to influence the research agenda.

Furthermore, consumers manage their health and illness in complex ways and as such have needs that professionals and researchers are not always aware of. By being involved in the research process consumers can provide important insights into problems caused by symptoms, health technologies (Goodare & Lockwood, 1999; Entwistle, Renfrew, Yearly, Forrester and Lamont, 1998; Chalmers, 1995; Telford et al., 2002; NHS Executive, 1999) and styles of service provision. They can also highlight the relevance of cultural, emotional and social issues (Telford et al., 2002).
Again consumer involvement could lead to improved consumer satisfaction if consumers felt that their needs were being taken into consideration. Thus, if consumer involvement in the NHS R&D meant that consumer needs and priorities were being used to shape the R&D programme, research would become more relevant to consumers, and any evidence derived from it could provide ways in which to change practice according to what consumers feel is important (Buckland & Gorin, 2001).

More generally, involving consumers in prioritising and setting the research agenda could have the result of reducing consumer mistrust for healthcare professionals. Consumers who become directly involved in this process could gain a better understanding of their condition and of the limitations of treatment options. They might, therefore, have more realistic expectations of healthcare professionals and be less dissatisfied at the end of the day. Furthermore consumers who benefit from the results of such research should feel that their needs are being better met. For example, if the service they receive is designed in terms of consumer preferences, consumers should have less to complain about. Equally, consumer involvement in the NHS R&D programme could act to legitimise it. If consumers are made aware of their involvement in certain research programmes they may better accept the resulting changes in service delivery (Entwistle et al., 1998).

Another result of consumer involvement in this part of the research process may be that consumers gain a feeling of empowerment, which many long-term service users currently feel they lack (Trivedi & Wykes, 2002). Some researchers have found that consumers who feel their views are being heard and used to change the service they receive develop better self-esteem and confidence (Macaulay et al., 1999).

A community might also develop an increased sense of ownership of a local service if they are involved in its development. In the author’s experience, communities who are actively involved in the development of a facility are much more likely to integrate it into their way of life and take pride in it. Grass root development projects in Kemataka use this principle to help disadvantaged communities improve their standard of living. In addition, a service that has been developed with consumers’
views and needs in mind should be aware of and sensitive to local cultural and social issues (Gott, Stevens, Small, and Hjelmeland Ahmedzai, 2002). In a sense getting consumers involved in prioritising and/or setting research questions provides a framework to respond to health issues within a social and historical context (Macaulay et al., 1999).

As such involving consumers in NHS R&D could have positive implications for consumer satisfaction. If consumers have fewer complaints about the service they receive; if they recognise the power the R&D policy gives them to improve the services they receive; if they begin to feel like ‘owners’ of the services available to their community it is likely they would begin to feel more satisfied. Thus, if good practice is defined by consumer satisfaction, consumer involvement in NHS R&D may be a good way of achieving it.

2.2 Improved Research Quality as a result of Consumer Involvement

It is important to recognise that, although consumer involvement in NHS R&D could have a positive impact on consumer satisfaction with services, this is only possible if the research carried out is reliable. In fact consumer involvement in NHS R&D should increase or at least not reduce the quality of research being carried out if it is to have any benefits at all. So in what way does consumer involvement improve the quality of research?

The main argument for the involvement of consumers in research is that they have knowledge and expertise that professionals do not. They have experience of what it feels like to suffer from a particular condition and receive treatment for it. They can offer a different perspective on issues relating to illness, treatment and outcomes. As such their involvement helps promote a certain open-mindedness about which research questions are worth addressing, which forms of treatment are worth assessing and which outcomes are worth measuring (Chalmers, 1995). They could also help prevent unnecessary and trivial research from being carried out (Entwistle et al., 1998; Oliver, 1995; Chalmers, 1995; Goodare & Smith, 1995).
Consumers can also improve the quality of research by helping researchers recruit participants (Hanley et al., 2001). Consumer groups often have contact with a wide variety of individuals who have relevant experience and who as a result are often motivated to promote change. Consumers groups may also have better means of reaching marginalized groups who are often not included in this kind of research (Hanley, Bradburn, Gorin, Barnes, Evans and Goodare, 2000). Furthermore, consumers can help ensure that research that addresses more relevant issues is actually carried out. They can act as powerful advocates for certain research projects, and convince researchers and funders alike of their merit (Hanley et al., 2001; Entwistle et al., 1998). They can also provide important insights into how to improve the experience of research procedures for participants (Hanley et al., 2001; Goodare & Smith, 1995; Buckland & Gorin, 2001). This might involve refining the information provided to participants (Hanley et al., 2001), or ensuring it addressed their ethical concerns (Buckland & Gorin, 2001). Some researchers have suggested that consumer involvement in research increases the sense of ‘ownership’ for all those involved including the researchers (Hanley et al., 2001). This could increase the chance of participants completing trials and reduce the chance of projects being cancelled at great cost to the R&D community (Goodare & Smith, 1995; Buckland & Gorin, 2001).

As such it seems consumer involvement in NHS R&D can be useful in terms of promoting open-minded about what questions to ask and how to ask them, recruiting appropriate, motivated and diverse participants and improving the likelihood of relevant research actually being carried out. This would suggest that consumer involvement in NHS R&D has the potential to improve research quality.

2.3 Improved Implementation as a result of Consumer Involvement

Although we have suggested that consumer involvement in R&D could lead to improved practice by improving consumer satisfaction and research quality, this can only be the case if the knowledge derived from this research is well disseminated and implemented. What can consumers do for the dissemination and implementation of knowledge?
Consumer groups often have very large membership lists, which will include consumers and professionals with an interest in the focus of the group. They also often distribute newsletters and or research summaries in which research results can be reported. The language used in these documents is often carefully chosen in order to make the information more accessible. Thus results can be easily disseminated to healthcare professionals who can directly implement changes and to consumers who can demand changes are implemented by healthcare professionals. Furthermore, consumer groups can improve the dissemination of research evidence by insisting that results get published in professional journals (Goodare & Smith, 1995). Once this has occurred consumer involvement in R&D should in itself improve the implementation of research evidence by improving the relevance and thus acceptance of the research (Entwistle et al., 1998).

In conclusion therefore it seems possible that consumer involvement is “more likely to produce results that can be used to improve practice” because it can have a positive impact on consumer satisfaction, research quality and research dissemination and implementation. However is it reasonable to only take consumer views into consideration? Furthermore, is it realistic to suggest that all the effects of consumer involvement are beneficial?

3 Limitations of Consumer Involvement

3.1 Representation, Realism and Good Practice
One of the main difficulties researchers seem to have with consumer involvement is understanding which consumers are likely to be most representative (Entwistle et al., 1998; Baxter, Thorne, Mitchell, 2000; Buckland & Gorin, 2001; Hanley et al., 2000). It seems clear that consumer involvement in NHS R&D is less likely to lead to consumer satisfaction if it does not take all, or at least all relevant, consumer views into consideration.

Consumers are not always unanimous in their opinions and researchers have questioned how they can be sure to obtain the whole range of consumer views (Telford et al., 2002; Baxter et al., 2000; Buckland & Gorin, 2001). In addition,
consumers who seek to become involved in research may do so because they have had a negative experience making them biased representatives (Telford et al., 2002). Furthermore, consumers who belong to consumer groups may not be good representatives for all consumers affected by a particular issue (Gott et al., 2002; Telford et al., 2002). They may not, for example, represent certain minority groups with valid cultural issues to contribute. Moreover, researchers have questioned how representative consumers are once they have undergone training to be involved in research projects. It has been suggested that they become ‘consumer-experts’ and as such loose their ability to give a lay consumer perspective (Buckland & Gorin, 2001).

As such, the difficulties involved in finding representative consumers to involve in R&D suggest that consumer views may not be equally taken into consideration and as a result that consumer involvement may not always lead to increased consumer satisfaction.

A further issue often brought up by researchers relates to consumers’ capacity to have a realistic understanding of healthcare provision and research and funding processes. They suggest that consumers can sometimes be very naïve about the research and funding issues (Hanley et al., 2001). They can also have unrealistic expectations (Baxter et al., 2000; Macaulay et al., 1999) about what changes are possible. They may not for example be aware of the intricacies involved in providing long term care or care for individuals who suffer from multiple conditions (Dunning & Needham, 1994). Some researchers suggest that there is a conflict between the role of the consumer and that of the researcher who has to keep practical issues like cost effectiveness in mind (Hanley et al., 2001).

Hence, although consumer involvement in NHS R&D could make the R&D programme more relevant to some it may not make it relevant to all. Further, consumer views about healthcare provision may not be practical. As a result, it seems consumer involvement in NHS R&D may not be the answer to consumer satisfaction or good practice, because what satisfies some will not satisfy others and because consumers may not be able to see the bigger picture. Professionals on the
other hand are able to see the bigger picture because of years of experience working for the Health Service (Hanley et al., 2001).

3.2 Research Quality at Risk
Researchers with experience of consumer involvement have made a number of observations about the ways in which consumer involvement is likely to hinder the research process.

One of the common observations made by researchers is that involving consumers takes time and money. Researchers have found that it takes time to find appropriate consumers, to convince them to take part, to train them and then finally to involve them in whichever way has been decided (Oliver, 1995; Gott et al., 2002). They point out that researchers themselves may require training on how to involve consumers (Dunning & Needham, 1994; NHS Executive, 2000). In some cases there may be a need for organisational changes in order for procedures to be implemented correctly (Dunning & Needham, 1994; NHS Executive, 2000). Since time and money are not available in unlimited quantities it is likely that this will lead to fewer research projects being carried out. This could slow the development of new technologies, the acquisition of knowledge and as a result progress towards good or improved practice.

Another observation made by researchers is that consumer involvement in NHS R&D requires professionals to hand over a certain amount of power (Gott et al., 2002; Baxter et al., 2000). This is often a difficult process to which professionals are likely to resist. The result may be a certain amount of inertia on the part of professionals (Dunning & Needham, 1994) or tension between consumer and professional perspectives (Gott et al., 2002; Telford et al., 2002) both of which could hinder the research process. Similarly, some researchers have suggested that the prospect of being audited and inspected to ensure consumer involvement in NHS R&D may provoke a defensive reaction from some providers (Gott et al., 2002). If consumer involvement becomes a priority as a political imperative, there is a risk that the quality of resulting decisions will become secondary (Entwistle et al., 1998).
The quality of research being carried out could thus be jeopardised by the time and money required to involve consumers. It may also suffer the consequences of organisational and professional politics. In light of the fact that consumer involvement in NHS R&D may not be the answer to consumer satisfaction, it seems less and less likely that consumer involvement could contribute to improved practice.

3.3 Dissemination not the answer to Implementation

As we mentioned above (see part 2.3) consumer groups could improve dissemination in a number of ways. However this is only effective as a means of dissemination if professionals have time to then read this research. In the authors experience professionals often have very little time to update their knowledge and this sometimes results in them using outdated methods for years after they have been invalidated (Dunning & Needham, 1994).

It is also important to note that published papers do not report on consumer involvement. Publishers do not currently require authors to describe the ways in which consumers have been involved in their research. This could further limit the impact of this research on practice (Telford et al., 2002).

Consumer involvement in NHS R&D presents a number of problems to the R&D community. They are not sure who to involve. They are not sure if those they involve will be able to make practical contributions. They are not sure where they will get the time and money to implement the necessary changes. They are concerned that professionals will resist the loss of power that is involved. They are concerned that the quality of research will be at risk and they are unsure what impact this research will have on practice. These points suggest a number of important reasons why consumer involvement might not produce results that could be used to improve practice. Why then does the government now stipulate that consumers should be involved in various stages of the research process in the Research Governance Framework for Health and Social Care (DoH, 2003)?
4 Consumer Responses

Consumers have published a number of responses to the various objections people have made to consumer involvement in NHS R&D. Each of the points raised in part 3 will be addressed in turn.

4.1 Consumer Representation

Consumers accept that they have many different views on health related issues and that it is difficult to find a ‘typical’ consumer. They suggest that researchers should seek to obtain a consumer perspective rather than a consumer representative (Buckland & Gorin, 2001). This might involve giving consumers time to consult or involving a consumer who was able to give a consumer perspective despite any personal biases or extra knowledge.

In response to the argument that consumers are biased and therefore jeopardise the objectivity of the research process, consumers remind us that no one is truly objective or neutral. Theoretical and empirical work on the philosophy and sociology of science has shown that the culture and values of those involved can influence research and the knowledge derived from it (Entwistle et al., 1998). They argue that consumers bring a particular knowledge that is otherwise lacking and that this helps keep research focused on the fundamental reasons for undertaking the research (Hanley et al., 2000).

4.2 Consumer Understanding and Realism

Professional fears about consumers’ ability to understand and be realistic about health related issues and the research process have now been invalidated. There are now numerous examples of consumers demonstrating that this is not an issue. In some cases consumers have had training to develop their understanding of the research topic and process. In others consumers have been chosen for their existing knowledge of the issue and process. As mentioned earlier, such consumer experts are valid collaborators as long as they are able to provide a consumer perspective (Hanley et al., 2000).
4.3 Time, Money and Power
The concerns professionals have expressed about time, money and the balance of power suggest that they have not grasped the value or necessity of consumer involvement. Consumers argue that professionals need to accept experience as a valuable resource and that even if consumer involvement entails a loss of power it also entails a gain in knowledge which is the ultimate aim of the research process (Goodare & Lockwood, 1999).

4.4 Research Quality
Professionals who fear a decline in research quality as a result of consumer involvement seem to have forgotten that Consumers in NHS Research exist to protect the quality of research involving consumers (NHS Executive, 2000). Consequently, should consumer involvement prove not to benefit the research process it seems fair to assume that the Department of Health would remove the relevant policy from the Research Governance Framework for Health and Social Care. It is important to note however that consumer involvement is most likely to hinder the research process if it is not implemented correctly. Consumers warn that research and practice are more likely to benefit from consumer involvement if consumers are involved as collaborators rather than as consultants. If they are involved as consultants there is a risk that their views will not be taken into account and that they will only impact on the research process by taking up time and money to be trained and interviewed (Hanley et al., 2000).

Consequently it seems that consumer involvement in the NHS R&D programme may be “more likely to produce result that can be used to improve practice” if consumer and professional views are equally taken into consideration. In other words there needs to be collaboration between consumers and professionals. This may not be an easy policy to implement but the benefits to the consumer – healthcare professional relationship and to research and practice quality outweigh the limitations.
5 Implications for the Role of the Clinical Psychologist

Clinical Psychologists have two roles within the NHS. They are both researchers and clinicians. We shall thus describe the implications of the Consumers in NHS Research statement for each of these roles.

5.1 The Clinical Psychologist as a Researcher

If consumer involvement in research is more likely to produce results that can be used to improve practice, as we concluded above, the Clinical Psychologist Researcher would have a duty to ensure that consumers were involved appropriately in every stage of any research they carried out.

As such they would become responsible for identifying and contacting relevant consumers. Once this had been achieved the Psychologist would have to invite the consumers to participate in the research process. This might involve a presentation detailing the reasons why the NHS and the particular research group want them to be involved, the ways in which they would be involved and the benefits of their involvement. The Psychologist would have to develop a positive relationship with them in order to promote an effective collaboration. As a result of building these relationships the Psychologist may bridge the gap between the NHS and the community.

The Psychologist would also be responsible for training consumers before they become involved in the research process, in order to give them a better understanding of research and funding procedures. Depending on the type of consumer and the research topic being considered, the Psychologist might also attempt to develop the consumers’ understanding of the issue at hand.

Once consumers have been trained to understand the research and funding procedures, the Psychologist researcher would become a facilitator. In other words, the Psychologist could be responsible for facilitating the incorporation of consumer views into the research process. This might happen in a number of ways. For example, the Psychologist could ensure that consumers are not subject to intimidation and feel able to express their views. He or she could translate consumer views into research
questions and methodology. Since consumers are often interested in outcomes that
have not previously been considered, there are not always the tools available to
measure them with (Trivedi & Wykes, 2002). In this case the Psychologist could
facilitate the development of appropriate tools so that outcomes that are important to
consumers can be measured. The psychologist could also review texts written by
consumers for the dissemination of research results to ensure that they are not
oversimplified or misinterpreted.

In view of many reports on consumer involvement that describe tension between
professionals and consumers during this process (Gott et al., 2002), Psychologists
could also become mediators. In other words they may help resolve conflict between
the two groups and try to find ways in which both perspectives are incorporated into
the resulting research.

Consequently, if consumer involvement in NHS R&D is in fact likely to produce
results that can be used to improve practice, the role of the Clinical Psychologist
Researcher might involve bridging a gap between the NHS and the community,
becoming a teacher, a facilitator and a mediator.

5.2 The Clinical Psychologist as a Clinician
The consequences of consumer involvement in NHS R&D becoming mandatory
could have dramatic implications for the Clinical Psychologist as a clinician.
Currently, in the authors' experience, consumers of Psychological services generally
have very little knowledge of Psychological interventions. If consumer involvement
in research improves the dissemination of information, Psychologists may find that
their clients ask to become involved in the selection of a Psychological approach. This
has been the experience of medical doctors following the advent of the internet which
hosts sites like NHS Direct that exist to disseminate information on health related
issues. As such Clinical Psychologists may have to become advisors as well as
practitioners.

As we described above, consumers often have different priorities to those of
professionals. As a result psychological interventions developed on the basis of
Consumer views could have very different objectives. A change in the objectives of psychological interventions implies a change in the objectives of the Psychologist. As such, psychologists may need to focus on empowering their clients and enhancing their self-esteem rather than reducing their symptoms.

The implications we have described above are likely to have an effect on the balance of power between a therapist and their client. It seems likely that they will cause a balancing out of the power differential and this would have important consequences for the therapeutic alliance. We may find a generalisation of the collaborative process that is typical of Cognitive Behavioural interventions.

In conclusion therefore, consumer involvement in the NHS Research will be "more likely produce results that can be used to improve practice" if consumer and professional views are given equal weight and if consumers are involved in the research process as collaborators. As such, research will address more relevant issues, perhaps become more reliable and perhaps better implemented. In turn practice may develop to address the priorities of both consumers and professionals, which could in turn lead to the satisfaction of both parties. Consumers may feel more empowered and professionals better skilled to tackle their needs. This policy has important implications for all professions however Clinical Psychologists in particular are likely to develop their skills as communicators, teachers, facilitators, mediators, advisors and collaborators.
References


How can Bowlby's attachment theory assist us in understanding challenging behaviour in people with a learning disability?

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Year 1
The term challenging behaviour (CB) was coined to describe a huge variety of unusual and often dangerous behaviours displayed by certain people with a learning disability (LD). These behaviours can have serious social and sometimes physical consequences for the person as well as for those around them. Unfortunately they are relatively common and often poorly dealt with. It is perhaps because they are often poorly dealt with that they are also often very persistent (McGill, Clare and Murphy, 1996).

Until quite recently CB was considered to be a symptom of LD. As a result, in the 1950’s CB was often managed through the use of arm splints, camisoles and straight jackets. Although these practices were deemed inhumane and unethical by the 1970’s, they were replaced by punishment procedures that are perceived to be equally inhumane and unethical by modern day standards (Axelrod, 1986).

In the 1980’s clinicians began to consider the possibility that CB has a function and this inspired the use of new techniques such as structural and functional analysis. These techniques were used to gain a better understanding of CB from the perspective of the person with LD. As such, clinicians began to take the cognitive and emotional processes of people with LD into account when attempting to understand their behaviour.

In 1992, the World Health Organisation introduced a new definition of LD that highlights the importance of holistic approaches to understanding individual need which take into account all aspects of a person’s functioning within the context of their own life and relationships. It is in this context that the generalisation of Bowlby’s attachment theory to people with LD has been investigated (Smith and McCarthy, 1996).

In the following essay I shall discuss how attachment theory can assist us in our understanding of CB in people with LD. I shall begin by giving a brief account of the current definition, prevalence and epidemiology of CB as well as some of the proposed aetiologies. I shall then give a brief account of attachment theory as it currently stands and of its contribution to our understanding difficult behaviour in
other populations. This will lead to a discussion about the applicability of attachment theory to an LD population and the consequences for our understanding and of CB.

1 Challenging behaviour in people with learning disabilities

1.1 Definition

CB is a term often misused within LD services as a reference to any difficult behaviour. The formal definition of CB is actually:

‘Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities’ (Emerson et al., 1987)

In this sense CB includes all behaviours that put the person or those around the person at risk of physical harm and all behaviours that are sufficiently socially unacceptable as to cause exclusion from mainstream society. As this suggests, there are a huge variety of behaviours that can be described as challenging behaviours. In five broad categories they include aggression to others, self-injurious behaviour, damage to the environment, inappropriate personal behaviours such as smearing and spitting and resistant behaviours such as stereotyped or repetitive behaviours.

The consequences of these behaviours are extensive. The consequences for the person who exhibits the behaviour have been shown to include potential physical harm, being placed out of home earlier in life, being readmitted to hospital (Lowe, Felce, Perry, Baxter and Jones, 1998), being excluded from services (Emerson et al, 1987), social exclusion, abuse (Felce, Lowe & Perry, 2000) and being administered psychotropic medication (Emerson, 1995). The consequences for the person’s carers have been shown to include potential physical harm, a significantly increased burden of care (Emerson et al 1987), significant stress (Emerson, 1995) and high healthcare and social costs (Felce et al, 2000). Thus it seems CB includes a large number of behaviours that have extensive negative consequences. What do we know about its prevalence and epidemiology?
1.2 Prevalence and Epidemiology

In a survey of seven health districts in the North West of the United Kingdom, Qureshi and Alborz (1992) found that a total of 16.7% (or one in six) of people with LD presented with CB. This represented between 1.5 and 2.5 individuals in every 10000 people in the general population depending on the district. They also found that 5-10% of people with LD present with serious CB, where seriousness is characterised by increased frequency, duration, staff involvement, damage or harm. This represents 42 individuals out of every 220000 people in the general population.

The prevalence of CB in people with LD has been shown to increase during childhood, reaching a peak between the ages of 15 and 34 and declining from then on. It has also been shown to positively correlate with degree of intellectual impairment (Borthwick-Duffy, 1994) and to be associated with psychiatric symptoms (Moss et al, 2000) and personality disorder (Flynn, Matthews and Hollins, 2002). CB is also more likely to be identified in males than in females (Borthwick-Duffy, 1994). Studies looking specifically at self-injurious behaviour have found that it is more common in individuals with autistic features, poor communication skills, sensory impairments, epilepsy and certain genetic conditions (McClintock, Hall and Oliver, 2003).

Thus CB is relatively common within the LD population and is related to age, gender and IQ as well as individual features of disability, psychopathology and personality. How has this information helped professionals understand CB?

1.3 Current Theories

CB is seen by some as a symptom of certain kinds of genetic or physical conditions associated with learning disabilities. The number self-injurers among those with conditions like Lesch-Nyhan Syndrome, that are known to involve reduced dopamine pathways, have caused some to examine the role the dopaminergic system in CB. In addition the number of self-injurers among those with sensory impairments and minor illnesses have provoked others to examine the role of the Opiatergic system, which lifts mood and numbs pain, in CB (Clarke, 1998). Treatments based on these approaches to understanding CB involve medication and Behaviour Therapy.
Others see CB as a side effect of certain psychiatric conditions. CB of increasing severity is associated with an increased prevalence of psychiatric symptoms. Depression is particularly associated with CB as a whole and anxiety with self-injurious behaviours in particular. In this case CB is described as a maladaptive way of coping with psychiatric symptoms (Moss et al 2000). Treatments based on this approach to understanding CB involve medication and Behaviour Therapy.

Further, CB could be perceived as a means of expressing emotions or needs for individuals who may not have the skills or abilities to express them in more adaptive ways. The fact that certain types of CB such as self-injurious and stereotyped behaviours are more common in individuals with autistic features, known to be associated with poor language and social skills, provides some support for this hypothesis. Interventions based on this understanding involve structural and functional analysis (Axelrod, 1986).

Unfortunately interventions based on these models of CB have limited efficacy. Research suggests that challenging behaviours are persistent over time, rarely eliminated and involve a high risk of reoccurrence following successful intervention (Emerson, 1995). Further none of these models follow the recommendations of the World Health Organisation (1992) to adopt holistic approaches to understanding people with learning disabilities that take into account their life experiences and relationships. Attachment theory is a framework that does take these factors into account and that has been used to explain deviant behaviour patterns in other populations. In the following section I shall describe attachment theory and examine the way it has been used to explain difficult behaviour in other populations.

2 Attachment Theory

2.1 Bowlby

In 1969, John Bowlby called attention to a biological attachment behavioural system for the regulation of primate safety and survival that he believed was as important as systems guiding feeding and reproduction. He noticed that most infants: a) continually monitor the availability of one or a few older attachment figures and b) flee to these
individuals as a haven of safety in times of alarm. As a result he suggested that the principal role of the attachment bond is to provide security, and is therefore defensive, in the positive sense of reducing anxiety. Furthermore, he suggested that the nature of the attachment bond influences the emotional and social development of the individual. In other words he was suggesting that a secure attachment is essential for the normative social and psychological development of the child. He believed that the infant uses early attachment experiences to develop an internal working model that later influences interpersonal perceptions, attitudes and expectations (Main, 1996).

At the same time, Bowlby developed the concepts of separation and loss1. At first he believed that separating the infant from the caregiver would inevitably result in trauma since it prevents the caregiver from responding to the attachment needs of the infant. He later suggested that separation can take place without traumatic consequences as long as it is handled sensitively within the family (Holmes, 1997). This was perhaps in response to the development of attachment theory instigated by the work of Mary Ainsworth.

2.2 Ainsworth

In 1978, Ainsworth, Blehar, Waters and Wall (cited in Allen, Aber and Leadbeater, 1990) took attachment theory a step further with the development of the Strange Situation procedure. In this procedure a 12-month infant and their primary caregiver are placed in a room containing several chairs and some toys. The behaviour of the infant and caregiver is then observed when they are both in the room alone, when they are in the room with a stranger and when the infant is in the room with the stranger. The observations that Ainsworth and her colleagues made under these conditions allowed them to expand Bowlby's original theory in three major ways.

First they introduced the notion of the caregiver as a secure base from which the infant explores surroundings. As such they identified attachment as playing an essential part in the development of autonomy and differentiated it from dependence. Second they identified three distinct styles of attachment: secure, insecure-avoidant and insecure-ambivalent. Third they introduced the concept of caregiver sensitivity as a determinant

1 He saw loss and separation as very similar in that loss was an irrevocable state of separation.
of attachment style. As such, the caregivers' ability to recognise and respond appropriately to the infants' attachment behaviours is seen as crucial for the normal psychological development of the individual (Main, 1996).

2.3 Main

In 1986, Main and Solomon introduced a fourth style of attachment that they described as insecure-disorganised. Based on observations of infant behaviour in the Strange Situation, they found that the attachment style of many previously unclassifiable infants could be described in this way. This attachment style tends to be associated with frightened or frightening care giving. The behaviour of insecure-disorganised infants is thus an expression of their inability to find a solution to the paradox of fearing the individuals who they wanted to approach in times of distress (Main and Hesse, 1990).

Main and her colleagues also developed a semi-structured interview to assess attachment in adults. The Adult Attachment Interview (AAI) looks at the coherence and thoughtfulness with which adults describe their childhood experiences and their effects in order to assess their state of mind with respect to attachment (George, Kaplan and Main, 1995; cited in Fonagy et al., 1996).

Although attachment theory has developed since Bowlby introduced it, many of its original tenets have received empirical support (Rutter, 1995). For example, studies looking at the distribution of attachment patterns across international samples have found that the majority of infants worldwide are secure and that there is greater variation in the distribution of attachment patterns within than between countries (Van Ijzendoorn and Sagi, 1999). Other studies have looked at the relationship between attachment and disruptive behaviour. They seem to fall into two main categories: those that look solely at behaviour problems and those that look at behaviour problems as a result of psychopathology. I shall give some examples of both and then describe the ways in which attachment theory has been used to explain these two types of problem behaviour.
2.4 Attachment Theory and difficult behaviour in non learning disabled populations

A number of studies have found evidence for a relationship between insecure attachment and disruptive behaviour in children and young adults. Looking at school age children, Erickson, Sroufe and Egeland (1985) found that the majority of children reported to have behaviour problems by their teachers had been insecurely attached in infancy. Lewis, Feiring, McGuffog and Jaskir (1984) found that attachment classification at 12 months predicted maternal reports of behaviour problems in 6-year-old boys with insecure-ambivalent boys showing more behaviour problems than all other groups. More recently, Turner (1999) found that insecure boys showed more aggressive, disruptive, assertive, controlling and attention-seeking behaviour towards their peers than insecure girls and secure children.

Other studies have found evidence for a relationship between disorganised attachment and disruptive behaviour and/or aggressive behaviour in children and adults. Disruptive aggressive school behaviour has also been associated with disorganised attachment status in both longitudinal (Goldberg, Magrill, Hale, Damaskinidou, Tham, 1995) and cross sectional (Greenberg, Speltz, DeKlyen and Enriga, 1991) studies. Disorganised attachment has also been linked with AAI categories that are commonly found in groups with criminal convictions (Hesse & Main, 2000) and violent relationships (Fonagy, 1999). In general, disorganised controlling attachment seems to be a general risk factor for maladaptive behaviour.

2.5 Attachment and problem behaviour in non learning-disabled populations in the context of psychopathology

Evidence exists for a relationship between insecure attachment and disruptive behaviour in the context psychopathology in both children and adults. The DSM-IV recognises the existence of Reactive Attachment Disorder (RAD) as one of the most severe forms of infant psychopathology (APA, 1994). It is characterised by an inability to form normal relationships with others and impairment in social development marked by sociopathic behaviours during early childhood (Wilson, 2001). Psychologists also recognise that the risk for RAD is increased by factors that contribute to abuse and neglect (Tibbitss-Kleber and Howell, 1985).
In adolescents admitted to a psychiatric facility, Rosenstein and Horowitz (1996) found that an overwhelming 97% reported feelings congruent with insecure attachment as described by the AAI (George et al., 1985). Those that were labelled dismissing (that is derogatory and cut off from their attachment experience) were associated with conduct and substance abuse.

Evidence also exists for a relationship between disorganised attachment and disruptive behaviour in the context of psychopathy. One study looking at attachment patterns in a group of severely personality disordered inpatients found that a high proportion (47%) of the inpatients diagnosed with Borderline Personality Disorder were classified as fearfully preoccupied according the AAI (Fonagy et al., 1996). These participants were all detained under the Mental Health Act (1986), which suggests a history of disruptive behaviour.

2.6 Theoretical explanations
These findings suggest a link between insecure and disorganised attachment during infancy and problem behaviour in later life. Several aspects of attachment theory can potentially account for this.

In the first instance, the nature of the primary attachment is said to have long lasting effects on people’s perception of themselves in relation to the world around them. Attachment style in infancy is said to affect a person’s behaviour towards others throughout life because it affects the internal working model that that person has in relation to others. Those that have insecure attachments in infancy develop poor internal working models of themselves in relation to others and may thus expect insensitivity, rejection and/or unreliability from others. Their behaviour towards others may thus be problematic as a reflection of these expectations.

In the second instance, attachment theory suggests that anger is a natural response to the actual separation and loss of parental figures or to the loss that occurs with real or perceived parental rejection. As such, children who are insecurely attached and whose
parents are chronically inconsistent or rejecting experience frequent and intense anger. Over time the child develops an internal working model of relationships in which anger and rejection are central features. This has consequences for the child’s relationships throughout life. Under some conditions the anger can be displaced onto other sources and may result in hostile and anti-social behaviour.

In the third instance, it has been suggested that disorganised attachment in early life may result in a general interpersonal incompetence on the part of the child, characterised by problems with affect regulation and social cognitive competency. These difficulties are likely to be present early in life and have important consequences for the child’s interaction with peers. Rejected peers tend to forge alliances with those that are similar to them and with whom they share an interest in deviant activities (Granot & Mayscless, 2001). As such, the effect of attachment style on children’s interpersonal competence may predispose them to long-term deviance.

Consequently, attachment theory provides a series of explanations for the relationship between insecure and disorganised attachment and problem behaviours in non-learning-disabled populations. This suggests that attachment theory may have something to contribute to our understanding of CB in people with LD. In the following section I shall examine the applicability of attachment theory to people with LD, the reasons why people with LD have a higher risk of developing insecure attachments than the normal population and models that have been put forward to explain the relationship between insecure attachment and CB.

3 Attachment Theory and Learning disabilities

3.1 Applicability

The applicability of attachment theory to people with LD has been demonstrated in several ways. There is first of all no evidence for an association between quality of attachment and general intelligence (Smith and McCarthy, 1996). In other words people with LD have the same styles of attachment as the non-learning disabled population. Further, people with LD have been found to traverse the same developmental phases of attachment-separation as the normal population, albeit in a
different timescale. This was noted by Joan Bicknell (1983) and a number of psychoanalysts including Neville Symington (1981) and Valerie Sinason (1986) who pioneered the use attachment theory with this client group.

However, although attachment theory is applicable to the LD population, attachment patterns do not appear to be distributed in the same way within it. In a meta-analysis of studies, Van Ijzendoorn, Schuengel and Bakermans-Kranenburg (1999) found that significantly fewer people with ‘neurological abnormalities’ had secure attachments that in the normal population. In addition, they found that significantly more had disorganised attachments. In the following section I shall examine some of the reasons why people with LD have an elevated risk of having insecure attachments.

### 3.2 Learning disabilities and insecure attachment

There are a number of ways in which a LD affects the relationship between a parent and their child. They can broadly be separated into two categories: those that arise from changes in the primary caregiver’s behaviour and those that arise from differences in the way the child with LD develops.

From the moment an infant is diagnosed as having a LD, the parents are said to experience the loss of their ‘perfect’ child. Having a baby that is in some way ‘imperfect’ is a blow to a parent’s sense of self as a procreating being. Further the child may be seen as representing all the damaged aspects of the parents that they do not want (Sinason, 1992). The parents’ response to this loss follows a familiar pattern, which includes shock, denial and grief with an attempt to bargain and negotiate often leading to acceptance and change. Each of these responses is related to the significance of the disability present at the time and anticipated in the future. As such, many people with LD experience emotional rejection in early life.

In addition, people with LD can experience rejection in a concrete way. Since LD is associated with many physical and genetic conditions, the life expectancy of individuals with LD can be much lower than the national average. Beliefs about life expectancy can lead some parents to reject their baby by arranging for institutional care from a very early age. Other parents place their LD children in institutions
because they are unable to cope with the disability or because professionals advise
them to\(^2\). Historically institutional care has not been supportive of clients' emotional
development because of the low staff to client ratio and the high staff turnover. This
prevents clients from developing secure attachments and further predisposes them to
insecurity (Clegg and Lansdall-Welfare, 1995). Yet other parents reject their learning
disabled children by subjecting them to abuse (Sinason, 1992).

The parents of a learning disabled child may also find the child more difficult to
parent. Depending on the nature of the intellectual disability and the presence of
concurrent physical disabilities that parent may find it difficult to 'read' the child.
Children with Down Syndrome, for example, are less reactive and less clear in their
signalling behaviour which makes it more difficult for their parents to be sensitive
towards them and to meet their attachment needs (Van Ijzendoorn, Goldberg,
Kroonenberg and Frenkel, 1992). This may also be why many learning disabled
children are expected to carry out activities that are appropriate for the final stage of
attachment-separation, namely separation, although they are at an earlier stage of
development (Frankish, 1992).

Since the learning disabled child does not develop at the same rate as other 'normal'
children they often experience life transition events at different times in their life and
in a different order. The obvious difference between this experience of transitional
stages and the ideal experience imagined by the parents often provokes a
recapitulation of the original experience of loss (Goldberg et al, 1995). Over the years
this can deplete the family’s emotional resources. Parents often deny their feelings of
hurt, anger or guilt at having any negative feelings about their child at all. In order to
compensate for this guilt some parents become over-concerned about their children
and encourage excessive dependency. In these cases the parent and child often fail to
achieve the process of separation, which is essential for autonomy, because it would
mean having to face the original loss (Sinason, 1992). In my experience this causes
the person with LD to develop enmeshed relationships with care staff, when they live
in supervised accommodation.

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\(^2\) This occurred in the UK as recently as 20 years ago.
As a result it seems there are a number of reasons why people with LD might develop insecure attachments. This suggests that there are potentially very high numbers of individuals with insecure attachments in the LD population. In the following section I shall examine the relationship between insecure attachment and challenging behaviour in people with LD.

3.3 Attachment and CB in people with LD

In 2002, Clegg and Sheard conducted a survey of staff and carers involved with 54 school leavers with severe LD. They found that 34% of the school leavers were described in ways that suggested they were insecure in their attachments. These school leavers were also much more likely to show CB. In the same year, Flynn, Matthews and Hollins investigated the rate of personality disorders, known to be associated with poor attachment styles, in a sample of mild to moderate learning disabled adults with severe CB. 39% of their sample met criteria for severe personality disorder and this diagnosis was significantly associated with early traumatic experiences. This suggests that there is relationship between CB and poor attachment style. I shall describe a model that has been developed to explain this relationship.

Janssen, Schuengel and Stolk (2002) have suggested that difficulties with attachment cause CB by increasing the individual’s susceptibility to stress. Psychological stress is processed in two stages: the first where people evaluate events for their threat value and the second where they evaluate the availability and effectiveness of their coping strategies. Janssen and colleagues suggest that people with LD are at risk of psychological stress because they have difficulty with both of these stages. They are perhaps more likely to perceive events as stressful because of their cognitive impairments, their need for structured and predictable environments and their limited behavioural repertoire. They are also perhaps more likely to perceive themselves as unable to cope with the stressful event because of their low self-esteem, general feeling of incompetence and perception of their life as uncontrollable.

Janssen and colleagues then suggest that people with LD who are insecurely attached are even more likely to perceive themselves as unable to cope with stressful events
because they find felt security so difficult to achieve. In this way people with LD who are insecurely attached may perceive stress in a more frequent, intense and sustained manner than the general population. In turn this may put the biological response system of these individuals into an almost permanent state of activation, which results in the development of hard wired maladaptive responses to even low levels of stress.

This has been shown to provoke difficult behaviour in other populations with poor attachment styles. Insecurely attached children distort and exaggerate attachment behaviours in an effort to maintain the availability of their attachment figure (Main, 1990). Further, disorganised children display disorganised behaviour reflecting a breakdown of coping strategies in the presence of their fear provoking attachment figure (Van Ijzendoorn et al, 1999). Finally, in the long term this has been associated with dissociation which could be associated with self injurious behaviour in people with LD (Russ et al 1992).

In this sense, it seems that CB may be a maladaptive response to sustained and frequent psychological stress caused at least in part by a lack of attachment security. This could account for the relationship between CB and level of disability since more severely disabled individuals will perceive themselves as even less able to cope with perceived stress. It would also account for the relationship between CB and age since maladaptive responses are thought to develop after sustained stress. However are there not limits to this understanding of CB?

4 Limitations of using attachment theory to understand CB

4.1 Diversity of the population

As we have seen, attachment theory seems to lend itself well to explaining challenging behaviour in people with LD. However it is surprising how often the literature refers to this population in broad terms. In reality the LD population is an extremely diverse group ranging from those that are very mildly intellectually impaired to those that are severely impaired with multiple additional physical problems. As such it seems difficult to understand how the general themes I have described can be applied to all members of this group.
4.2 Measurement Issues
In addition, it is not clear that Ainsworth’s classification system is appropriate for those with LD. The Strange Situation was developed on the basis of observations of non-clinical samples and has therefore not been validated for this population. Although it seems clear that people with LD develop the same styles of attachments as people without LD, it is not clear that their behaviours follow exactly the same pattern for each style of attachment. There are virtually no studies of the home behaviour-Strange Situation classification mappings for children with disabling conditions. Without such studies, there is no way of determining the psychological meaning and antecedents of attachment patterns for these children even when the patterns of behaviour seem similar. As such, the results of studies using the Strange Situation let alone adapted versions of the Strange Situation should be treated with caution since they are based on non-validated methods (Vaugn et al, 1994). The only validated measure of attachment is the semi-structured interview for adults with LD developed by Smith and McCarthy (1996).

4.3 Causality
Finally, it is important not to attribute too much to the infant attachment pattern of the person with LD. Attachment theorists have often been criticized for offering an ‘inoculation’ theory of development where secure attachments prevent all future harm and insecure attachments put the child at risk or even cause subsequent problems. Bowlby (1980) stated quite clearly that people’s internal working models could change in response to real world experiences. It is therefore important to consider concurrent relationships as well as historical relationships when trying to understand challenging behaviour. In addition, research suggests that there are many variables that contribute to disruptive behaviour problems in normal populations (Greenberg et al, 1993). As a result we should perhaps be asking whether attachment difficulties have causal or mediating effects on disruptive behaviour? or whether attachment problems and disruptive behaviour are both consequences of the same complex of social, biological and situational variables? Waters, Posada, Crowell and Keng-ling (1993) feel it is too early to tell.
In conclusion CB is a condition that affects large numbers of people with LD, with varied and serious consequences for all those involved. Current understandings and interventions for CB are often ineffective perhaps because they do not take account of people's history. With this in mind I have described attachment theory and the way insecure attachment has been used to explain disruptive behaviour in non-LD populations. I have then considered the various reasons why LD populations seem to be at risk of developing insecure attachments and explored the ways in which this might predispose individuals to developing CB by making them more susceptible to stress. Finally I have considered the limitations of using attachment theory to understand challenging behaviour, namely the diversity of the LD population, the lack of validated assessment tools and the questionable causality.

Although it may be too early in the development of attachment theory to ascertain whether attachment styles influence the development of challenging behaviour in people with LD, it may still be helpful to use the theory for prevention and intervention. As such even if a behaviour cannot be traced back to attachment problems, it can impact on concurrent relationships which may have long-term implications. It is therefore useful and important to set therapeutic goals that include diminishing challenging behaviours and establishing a secure base.
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"Divorce is bad for children". Critically discuss with reference to the literature on the psychological effects on children of divorce and parental conflict.

January 2005
Year 2
Since the 1970’s the rate of divorce has increased dramatically in western countries. According to the Office for National Statistics, in the United Kingdom the rate of divorce has increased from approximately 33000 in 1950 to 154000 in 2001 (Office of National Statistics, 2001). In 1998, this meant that 19% of children born to married couples would experience divorce by the time they were 10 years old and 28% by the time they were 16 years old (Rogers & Pryor cited in Dowling & Barnes, 2000). At first, this trend was seen by many social scientists as social progress. It seemed that unhappy couples no longer felt obliged to stay together and could free themselves and their children from the burden of marital conflict. However by the end of the 1980’s, research suggested that divorce has many negative effects and particularly for children. This evidence has been interpreted in different ways, some would say depending on individual’s political inclinations (Coltrane & Adams, 2003). As such, some have concluded that changes in family structure have major negative consequences for the psychological well being of children and for society as a whole. On the other hand, others have concluded that factors associated with changes in family structure, rather than changes in family structure per se, have negative consequences for the psychological well being of children. In the following essay I shall examine the evidence and arguments presented by both groups, with particular focus on the psychological effects of divorce and conflict on children, in an effort to answer the question: Is divorce bad for children?

1 Comment

I chose to write this essay because of my personal experience of parental divorce and as a result of this experience I have found the process of researching this essay particularly difficult. Although I began the process with certain preconceived ideas I now find that some of my ideas have changed. I would like to share some of my reflections with you to illustrate some of my points and the evolution of my thoughts.

2 Divorce: a definition and a description

Divorce is generally defined as the legal dissolution of a marriage. In this sense divorce is a legal procedure carried out by solicitors that involves making an official
record of the dissolution of a state registered marriage. However in the following essay and in much of the literature we shall discuss, divorce is defined as a process that involves the gradual deterioration of the marital relationship, the couple’s separation and the following period of adjustment (Wallerstein, 1991; Hetherington, 1989).

As one might imagine, divorce exists in many different forms. Evidence suggests that in some cases the deterioration of the marital relationship involves high levels of conflict and poor communication and in other it involves a gradual loss of love, diminished mutual regard and divergent life styles (Dreman, 2000). Further evidence suggests in some cases separation involves the father moving out of the family home, in others it involves the mother moving out of the family home and in others in involves the couple taking separate bedrooms (Cockett & Tripp, 1994). Further research indicates that in some cases the following period of adjustment involves high levels of conflict, some of which children are directly drawn into, and in others it involves cooperation, negotiation and compromise (Dreman, 2000). Research suggests that the period following separation can also involve legal proceedings over children’s custody, the distribution of families’ material possessions and future financial contributions. As a result of the decisions made around these issues families might find it necessary to move home and/or change schools. Finally children can sometimes experience a loss of contact with family members such as non-custodial parents and extended family relatives such as grandparents, aunts, uncles and cousins (Cockett & Tripp, 1994).

3 Divorce is bad for children
In response to the steep rise in marital breakdown described above, a large body of research examined the effects of divorce on children throughout the 1970’s and 80’s. In 1991, Amato and Keith published a meta-analysis of 92 of the quantitative studies conducted during this period and concluded that overall children from divorced families experience lower levels of well being in the domains of psychological adjustment, self-esteem, conduct, academic achievement, social competence and in their relationships with parents than children from intact families.
In 2000, Wallerstein Lewis and Blakeslee (as cited in Wallerstein & Lewis, 2004) reported on a qualitative longitudinal study of the social and psychological experiences of adults and children at the time of marital break-up and during post-divorce years. This study began in 1971 and involved observations and interviews of 131 children, their parents and their teachers, 5, 10, 15 and 25-years following parental divorce. It remains the single most enduring investigation into the long-term effects of divorce and in consensus with quantitative research conducted at the time suggests overall negative consequences for children of divorce.

As such, Wallerstein and her colleagues found that 5 years after parental divorce more than a third of the children they interviewed had moderate to severe depression, poor academic achievements and social difficulties. 5 years later many of the young men and women they interviewed were “troubled, drifting and underachieving” (Wallerstein, 1991, p.353) and even those who were doing well during adolescence became prone to psychological distress and anxiety about forming relationships in early adulthood. 15 years after parental divorce many entered psychotherapy to work through issues around their parents’ divorce and their own relationships (Wallerstein, 1991). At the 25-year follow up, Wallerstein and Lewis (2004) claim that the effects of divorce are cumulative and peak when people are at the threshold of adulthood and having to make decisions about love, commitment and marriage. They suggest that adult children of divorce lack a successful model of relationships and make poor relationship choices and decisions as a result. They further suggest that they are unlikely to be as close to their parents as children from intact families. Most importantly they propose that in the absence of overt violence or other parental psychopathology parents should stay together for sake of the children.

In summary therefore, the studies described above suggest that divorce has negative consequences in many domains of children’s lives and should even be avoided. I found reading about these studies quite painful because they reminded me of my experiences and because I recognised having suffered some of the negative outcomes myself. In this sense, reading about these studies made me feel like one of many victims of parental divorce. However I also recognised that there were many negative
aspects of the experience and outcomes associated with divorce that I had not experienced. This highlighted the variation in people’s experience of divorce, which I felt was not highlighted in this literature. In the following section I shall examine some of the other criticisms that have been made of the research described above for methodological, theoretical and political reasons.

4 Research Critique

4.1 Methodological issues with the research

One of the basic concerns raised in the literature is the tendency to confound correlation with cause in this field. As I have shown studies suggest that the negative outcomes detected in children of parental divorce are caused by divorce (Amato & Keith, 1991b). However in many cases studies have actually interpreted regression coefficients as representing causal effects. Since regression coefficients are basically correlations, they are subject to the premise ‘correlation does not imply causation’. As a result, these studies should be reporting that negative outcomes in children are more likely after parental divorce and not that the two are causally related (Bhrolchain, 2001).

Another concern raised is for the tendency to make causal links between parental divorce and later outcomes despite the lack of statistical controls and control groups in a lot of the literature in this field. In a review of 84 of the 92 studies included in Amato and Keith’s (1991b) meta-analysis, Jameson (cited in Bhrolchain, 2001) found that most used no statistical controls at all. Furthermore Wallerstein (Wallerstein & Lewis, 2004) has been criticised for not using a control group in her longitudinal and qualitative study apart from for the 25-year analysis. Including controls allows for some certainty that the outcomes measured are not caused by some other unmeasured variable or by individual differences.

Concerns also exist about the tendency for cross sectional studies in this field to make causal links between parental divorce and later outcomes despite the time confounds that they produce. In order to be sure that outcomes relate unambiguously to the post-divorce period researchers should take measurements before and after the divorce
(Bhrolchain, 2001). Further time confounds exist in the literature that are not simply related to cross-sectional studies but also to longitudinal studies who's sample experienced divorce in the 1960's or 1970's. Amato (2001) reports that the difference between the scores of children of divorced and non-divorced parents on measures of academic achievement, conduct, psychological adjustment and self concept collected since the 1960's and plotted on a graph reveal significant curvilinear trends. He reports that for most measures the differences were largest in the 1960's, smallest in the early 1980's and large again in the 1990's. Amato and Keith (1991b) suggest that a change in attitude towards divorce between the 1960's and 1980's supported by survey results could explain the initial reduction in effect sizes. He goes on to suggest that either a change in the nature of divorces or a rise in the economic advantage of two-parent families could explain the subsequent increase in effect sizes (Amato, 2001). Either way these variations affect the relevance of studies like the one conducted by Wallerstein and her colleagues to current populations (Wallerstein & Lewis, 2004).

Further concerns exist about the choice of samples in the divorce literature and the generalisations made from them. Kelly and Emery (2003) suggest that although studies generalise their results to entire populations many use relatively small, unrepresentative and sometimes highly select samples. They refer to Wallerstein and her colleagues in particular who generalise their results to the entire western population of white middleclass families although the parents of the children included in their study had an unusually high rate of severe psychological problems. It was also clear from the literature review conducted for this essay that there is a shortage of research looking at the effects of divorce on children from different ethnic backgrounds. In fact most research seems to be limited to white families.

As such, although the literature reviewed at the beginning of this essay suggested that divorce clearly resulted in numerous negative consequences for children it seems that methodological issues prevent us from accepting these conclusions. In the following section I shall examine some of the theoretical and political criticisms that have also been made of this literature.
4.2 Theoretical and political issues with the research

An apparent symptom of research conducted in the midst of social change is a bias towards outdated concepts and values. In a critique of one of Amato’s reviews (1993), Demo (1993) suggests that the language and logic of his hypothesis testing is biased in favour of finding deleterious effects of divorce on children. His comments about the weighting of significant and non-significant findings and the weighting of each study included in the review could be applied to several other reviews by the same author (Amato & Keith, 1991b; Amato, 2001). He goes on to suggest that the basic premise of the review, that children of divorce suffer life long adjustment problems, “reflects an insidious problem characterising most research in this area: the persistent (if often implicit) valuation of the traditional nuclear family” (p.42). In his view Amato and others are pre-occupied with trying to identify and explain deviations from the ideal family form and should focus on reflecting the realities of children’s lives and the family experiences impinging on those lives. In effect he criticises Amato and others for taking a problem oriented approach to divorce which is inconsistent with many children’s experiences not least those who have an abusive parent. Demo suggests that divorced and other types of family should be considered “normative lifestyle choices that are firmly established in society, rather than as social problems or pathological behaviours” (p.45) in accordance with Coleman and Ganong (cited in Demo, 1993).

Coltrane and Adams (2003) highlight the same bias in the literature but attribute it to the political agendas of certain social groups. As I mentioned in the introduction, divorce has not always been seen as a social problem. Coltrane and Adams claim that divorce was only socially defined as disagreeable when family moralists introduced it that way to the public. They claim that family moralists in the United States have a lot of power and are able to fund and disseminate the results of research programs, like the one carried out by Judith Wallerstein (Wallerstein & Lewis, 2004). Family moralists are accused of doing this in an effort to affirm the correctness of their own values. Coltrane and Adams suggest that when divorce became known as a social problem, family moralists and those associated with them began to own it. In other words family moralists and those associated with them became ‘experts’ on divorce and were able to change the language used about it through media coverage. The
language used in many of Wallerstein’s publications is clearly biased against divorced families. Although Amato (2003) attempts to defend her for this by suggesting that she is compelling to a general audience the fact that she uses the same language in journal articles (Wallerstein, 1991) suggests that her style is indicative of a more fundamental perspective. According to Coltrane and Adams this is an attempt to make divorce a consensus issue despite the methodological issues with the research. Luckily, studies reporting much fewer negative consequences for children of divorce have prompted the media to take a more discriminating look at divorce research (Kelly & Emery, 2003).

As such, I have referred to a large body of research that reports finding evidence of poorer psychological adjustment, social competence, self-esteem, academic achievements and conduct in children of divorce compared to children of continuously married parents. I have examined the numerous criticisms of the research including those around the common inference of causality and generality and those around the lack of objectivity in this field. As I will show in the following section, not all research in this area reports such negative outcomes for the children of divorce. Negative outcomes in more recent research are associated with factors that are sometimes associated with divorce rather than with divorce itself.

5 Divorce is not bad for all children

Shortly after the publication, and widespread media coverage of Judith Wallerstein’s book: The Unexpected Legacy of Divorce: A 25 Year Landmark Study (Wallerstein, Lewis & Blakeslee cited in Wallerstein & Lewis, 2004), Mavis Hetherington published a book of her own: For Better or For Worse (Hetherington & Kelly cited in Hetherington, 2003). Like Wallerstein, Hetherington was reporting on the results of a longitudinal study of the effects of divorce on children.

In her study, Hetherington compared children from three groups: a remarried mother-stepfather group, a non-remarried mother custody group and a non-divorce group. Six years after parental divorce, she found that children from divorced and remarried families were over-represented in three clusters. The “maladaptive” cluster was made
up primarily of boys who were aggressive, insecure and anxious and came from homes characterised by high levels of conflict and negative affect. The “opportunistic and competent” cluster was made up of children who were popular and outgoing but also slightly egocentric and manipulative. These children also tended to come from high conflict families. Finally, children included in the “caring and competent” cluster were competent and popular but with a capacity for warmth and compassion. These children were mostly girls who had been given or had taken the responsibility for younger siblings or ill and needy parents. They tended to have warm and supportive mothers. Although these results could be interpreted as revealing negative consequences of parental divorce, Hetherington later demonstrated that these were short-term consequences that eventually disappeared in most of her sample.

When Hetherington reported on the results of later analyses, she concluded that most children recover from divorce without long-term harm. Her results indicated that 25% of children with divorced parents reach adulthood with serious social, emotional and psychological problems compared to 10% of children with continuously married parents. In other words 75% or the vast majority reach adulthood as well-functioning individuals despite their parents divorce. Hetherington suggested that this was evidence that others had exaggerated the negative effects of parental divorce on children. Further, having been influenced by stress and coping theory (Rutter, 1987), Hetherington was keen to emphasise the role of complex interacting factors associated with the individual and the context in determining the vulnerability of children to negative outcomes following parental divorce.

Hetherington’s claims were all the more powerful because her methodology and her approach suggested more objective results. She used standardised psychological measures and included some pre-divorce measures. She also used a control group of non-divorced families matched to the experimental group on demographic characteristics although, it should be noted that her sample was also composed solely of well-educated, white middle class families, which prevents her results from being generalised to certain other populations. Further, Hetherington took a particular interest in the characteristics of the children, their family and their social environment,
which demonstrates a shift in focus away from family structure as advocated by Demo (1993). This suggests a less biased approach to the study of divorce.

So if 75% of children who experience divorce reach adulthood unscathed, what makes some divorces more harmful than others? Research supports Hetherington’s suggestion that there are factors associated with both the individual and the context that mediate the impact of divorce and account for these differences (Kelly & Emery, 2003). In the following section, I will briefly describe some of the risk factors associated with the individual and the context.

6 Risk factors

6.1 The Individual

The individual characteristics reliably associated with children’s vulnerability to negative outcomes following parental divorce include age, temperament and coping style.

As such, Healy, Stewart and Copeland (1993) found that young children have a greater tendency to blame themselves for their parents’ divorce and that self-blame is associated with lower perceived competence, more psychological symptoms and more behaviour problems. It has been suggested that the limited cognitive development of children of this age prevents them from accurately interpreting the circumstances in which their parents’ divorce occurred (Hetherington, Stanley-Hagan & Anderson cited in Dreman, 2000). It should be noted, however, that evidence on the long-term reactions of different age groups is inconsistent, possibly because of time confounds (Dreman, 2000). Moreover, Hetherington (1989) found that children with easy temperaments are more adaptable in the context of increased stress and high levels of support than children with difficult temperaments. This increased vulnerability may be partly attributable to parent-child interactions since these children are more likely to receive and elicit aversive responses from their parents with which they are less able to cope (Rutter, 1987). Furthermore, Sandler, Tein and West (1994) found that children who use active coping skills tend to adjust to divorce more quickly than children who rely on avoidance or distraction as coping mechanisms. The active
coping skills they observed include problem solving, which I have already suggested facilitates better adjustment (see age and cognitive development) and gathering social support, which I examine in more detail in the following section.

In summary children’s age, temperament and coping skills appear to impact on their ability to understand, adapt to and cope with their parents’ divorce. However as noted in a lot of the research, these characteristics predict negative outcomes in children of divorce because they impair these children’s abilities in the context of stress. This suggests that children with these characteristics would suffer similar negative outcomes in the context of other forms of stress apart from parental divorce.

6.2 The Context

The characteristics of children’s context associated with their vulnerability to negative outcomes following parental divorce include family demographic characteristics, custodial family financial circumstances, social support, parenting style, parental adjustment, loss of parent, custodial arrangements and parental remarriage. Parental conflict is another important risk factor but one that I shall examine in more detail in the following section.

Thus in terms of family demographic characteristics, low parental income and young parental age have been associated with adjustment problems in children of divorce (Aseltine, 1996). In families whose income declined following the divorce process, economic hardship often results in added stressors such as having to change residence and/or school. The number of such changes is a consistent predictor of children’s divorce adjustment (Aseltine, 1996). Whilst adding to the uncertainty of the post-divorce situation, such changes can also impact on the support systems available to parents, which can be crucial in buffering the effects of parental stress on children (Cochran & Niego, 1995 cited in Leon). There remains little research on the benefits of social support for children of divorce.

In terms of parenting style, research suggests that divorcing parents can have poorer parenting styles than married parents, possibly in response to the stress of marital disruption. This is associated with lower academic achievement, internalising
problems, externalising problems, reduced self-esteem and poorer social competence in their children (Hetherington & Clingempeel, 1992). On the other hand authoritative parenting predicted children's higher academic achievement and lower internalising and externalising problems (Amato & Gilbreth cited in Amato, 2000). Parents who find it particularly difficult to adjust to the post-divorce situation are also at increased risk of developing physical and mental health problems and of abusing alcohol and drugs. This further impacts on their parenting ability, their relationships with children and on the quality of the home environment. As one might expect poor parental adjustment of this nature is associated with impaired emotional, social and academic adjustment in children of divorce (Hetherington, 1999). It has been suggested that this reflects children's need for consistency, structure and support during the divorcing process, which is ultimately characterised by uncertainty (Dreman, 2000).

Children who experience parental divorce are also at risk of losing contact with friends, extended family and non-custodial parents. Hetherington and Kelly (as cited in Kelly & Emery, 2003) found that between 18% and 25% of children have no contact with their fathers 2-3 years after divorce. Research suggests that many children identify loss of contact with a parent as a primary negative aspect of divorce and that children report missing their fathers over time (Fabricius & Hall, 2000; Hetherington et al., 1992). Custodial arrangements can also negative consequences for children either because of the interaction between custody type and gender or because of the amount of contact allowed with the non-custodial parent. Evidence suggests that school age children adapt less well in the custody of opposite sex parents (Hetherington et al, 1989). However, evidence with regard to older children in inconsistent. Moreover, many children in the custody of their mothers, especially boys, want more time with their fathers (Hetherington et al, 1989) and those whose mothers attempt to prevent contact with fathers report resenting their mothers and have been found to adjust less well (Fabricius & Hall, 2000).

In summary therefore I have shown that in addition to some of children's individual characteristics, characteristics of the family context such as income, number of life changes, access to social support, parenting style and adjustment and custodial arrangements also predict negative outcomes in children following divorce. This has
made me aware of the complexity of my experience and that certain aspects of it are likely to have had a more negative impact than others. In the following section I take a closer look at conflict and consider the possibility that this and other factors described above are responsible for negative outcomes in children rather than the divorce process itself. I suggest that, as a stressful life event, divorce is often associated with these factors but cannot be made accountable for their impact on children.

7 The role of parental conflict
Parental conflict is a common characteristic of divorce (Hetherington, 1989). Evidence suggests that conflict following divorce is a consistent predictor of poor outcomes among children (Amato, 2000). Hetherington (1989; as cited in Vanderwater & Lansford, 1998) found that conflict predicted children's inclusion into her “maladaptive” and “opportunistic and competent” clusters and that direct conflict between divorcing parents, but not ‘encapsulated’ (conflict to which children are not exposed), is related to behaviour problems among adolescents. Conflict has also been associated with poor parenting, which we know has negative consequences for children. It is suggested that as a source of stress for parents it makes them less able to deal with their children (Hetherington et al., 1992). Further, conflict has been linked to attachment problems in children. Some have suggested that it interferes with children’s relationships with parents, resulting in emotional insecurity (Davies and Cummings, 1994). Parent-child relations might be especially negatively affected when children are drawn into conflict between their parents (Vanderwater & Lansford, 1998). This suggests that divorce involving high levels of parental conflict in front of children and/or involving children results in negative outcomes for those children.

On the other hand, evidence exists to suggest that parental conflict outside of the divorcing process has equally negative effects on children. Marital conflict in intact marriages and that children are aware of has been associated with a range of negative child outcomes including externalising problems such as conduct disorder, aggression and delinquency and internalising problems such as depression and anxiety (Grych &
Fincham, 1990). This suggests that parental conflict can result in negative outcomes for children who are exposed to it even when parents do not go on to divorce.

In fact, evidence suggests that children from intact families with high levels of parental conflict have lower psychological adjustment and self esteem than children from divorced families (Amato & Keith, 1991b). Further, evidence suggests that children from families with high levels of conflict prior to divorce actually benefit from the divorce process, whereas children from families with low levels of conflict prior to divorce suffer from the divorce process (Booth & Amato, 2001). This suggests that conflict may be a better predictor of children’s outcomes than family structure.

Research supporting this hypothesis includes a study carried out by Sun (2001) that demonstrates that children of divorce exhibit more academic, psychological and behavioural problems than children from intact families before the divorce has even taken place. Sun suggests that pre-divorce conflict could at least account for the psychological and behavioural problems she detected in children of divorce and reported by many in this field. In addition, Vanderwater and Lansford (2001) found that parental conflict impacts on children’s well being regardless of family structure. They reported that children in high-conflict families showed higher levels of externalising problems, internalising problems and social difficulties regardless of whether their parents were divorcing or not. In addition, longitudinal studies have provided support for this hypothesis by demonstrating that children’s functioning improves with time and as conflict probably subsides (Hetherington, 2003). Lastly, Kurdek and Berg (cited in Vanderwater & Lansford, 1998) found that cooperation between parents following divorce predicted better divorce adjustment and fewer problems among children. As such, the hypothesis that conflict is a better predictor of children’s outcomes than family structure seems supported by empirical evidence.

8 Conclusion
In conclusion, in our efforts to answer the question “is divorce bad for children?” I have examined evidence that suggests that children who experience parental divorce
experience lower levels of well being in the domains of psychological adjustment, self-esteem, conduct, academic achievement, social competence and in their relationships with parents than children from intact families. I have then suggested that this research is unreliable as a result of methodological, theoretical and political issues. I found that it is often characterised by the use of poor sampling techniques, psychometric measures, design and analysis. In addition I found that much of the research was biased in its approach to the issue because it was based on the idea that the traditional nuclear family is the best environment for children’s development. Further, I found that some of the research is likely to have been influenced by political groups looking to promote their views. As a result of these issues, I rejected the evidence provided by this research in favour of other evidence based on more methodologically robust techniques and theoretically objective approaches. This research suggested that although some children who experience parental divorce suffer long term psychological, emotional and social difficulties, 75% do not. In response to this evidence I examined the factors associated with individual children and the context in which they experience parental divorce that have been shown to increase the likelihood of negative outcomes. In a more detailed review of the literature on parental conflict I found that parental conflict is more consistently associated with negative child outcomes than divorce. As a result I suggest that parental conflict rather than parental divorce is bad for children.

When I started the process of researching this essay, I felt strongly that divorce was bad for children. I now realise that I had not considered the possibility of divorce without conflict or divorce following abusive relationships. I also recognise that my experience of losing what I used to call the “foundations” of my life was not related to the loss of a family per se but to the loss, albeit temporary, of supportive parents. This loss occurred because of several of the risk factors we have discussed especially parental conflict. In light of this and the points discussed above, I would suggest that clinicians work with parents to promote cooperation and limit children’s exposure to conflict and especially their involvement in parental conflict. Finally the lack of research using samples from different ethnic and economic backgrounds highlights the limits to the generality of the research and the need for further research including these groups.
References


What psychological models, theories and practices are helpful to clinical psychologists when working with instances of suspected and/or actual abuse?

August 2005
Year 2
Although the concept of “Granny-battering” was introduced in the mid 1970’s (Baker, 1975) it is still not widely recognised or understood. In the government’s most recent publication on the topic it is suggested that elder abuse affects approximately 500,000 people at any one time (House of Commons, 2004). However this figure is based on the results of a study carried out in 1992 using a sample of 2000 and an outdated definition of elder abuse (Ogg & Bennett, 1992). The House of Commons Health Committee considers the lack of more reliable figures on the prevalence of elder abuse in Britain to be evidence for the lack of attention the issue receives and criticises the Government for not doing more about it (House of Commons Health Committee, 2004). After all, evidence from the United States suggests that vulnerable adults who have suffered abuse are 3.1% more likely to die in the following three years than adults who have not suffered abuse, even after adjustment for co-morbidity and other factors associated with mortality (Lachs et al., 1998). Conducting a literature review for this essay revealed to me that psychologists have also neglected the topic of elder abuse. Most of the literature available appears in Social Work journals. In this essay we shall start to address this oversight by looking specifically at the role of clinical psychologists in the management of elder abuse and ask: what models, theories and practices might be helpful to clinical psychologist when working with instances of suspected and/or actual abuse? In order to answer this question we shall examine the definition of elder abuse provided by the department of health, the prevalence of elder abuse in other western countries, the theories that may be helpful to psychologists trying to understand the occurrence of elder abuse, the practices that may be helpful to psychologists working with instances of suspected abuse and the practices and models that are helpful to psychologists working with instances of actual abuse. The practices, theories and models described represent those that I would consider using when working with instances of suspected and/or actual abuse on the basis of my current experience and recent literature review.

1 What we know about elder abuse

1.1 Definitions

In an attempt to address the issue of elder abuse the Government produced guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults in a paper called “No Secrets” (Department of Health and Home Office (DoH and
HO), 2000). In this document the Department of Health gives a definition of elder abuse, which states:

"Abuse may consist of a single act or repeated acts. It may be physical, verbal or psychological, it may be an act of neglect or an omission to act, or it may occur when a vulnerable person is persuaded to enter into a financial or sexual transaction to which he or she has not consented, or cannot consent. Abuse can occur in any relationship and may result in significant harm to, or exploitation of, the person subjected to it." (p 9)

The different types of abuse referred to in the definition and described in the "No Secrets" document are:

- **physical abuse** which includes hitting, slapping, pushing, kicking, misuse of medication, restraint or inappropriate sanctions;
- **sexual abuse** which includes rape and sexual assault or sexual acts to which the vulnerable adult has not consented or could not consent or was pressured into consenting;
- **psychological abuse** which includes emotional abuse, threats or harm or abandonment, deprivation of contact, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, isolation or withdrawal from services or supportive networks;
- **financial or material abuse** which includes theft, fraud, exploitation, pressure in connection with wills, property or inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits;
- **neglect or acts of omission** which includes ignoring medical or physical care needs, failure to provide access to appropriate health, social care or educational services, the withholding of the necessities of life, such as medication, adequate nutrition and heating;
- **discriminatory abuse** which includes racist, sexist, that based on a person’s disability and other forms of harassment, slurs or similar treatment.

These definitions have been accepted by the House of Commons Health Committee (2004) and welcomed as a first step towards the promotion of meaningful research on this topic in Britain. The previous lack of consensus prevented the development of knowledge about elder abuse because it meant that research findings were not comparable (Eastman, 1994; Ogg & Munn-Giddings, 1993).
1.2 Prevalence

As well as having difficulties with definitions, research in this field has been marred by reporting and recording issues. It seems older adults who have suffered elder abuse cannot be relied upon to report this to professionals. Some are unable to report their experiences because of cognitive or physical impairment and those that could tend to be reluctant (Homer & Gilleard, 1990). In addition it seems staff in care settings cannot be relied upon to report cases of abuse. Staff often do not recognise, record or report cases of abuse (Richardson, Kitchen and Livingston, 2002). This suggests that cases detected by prevalence studies represent just the “tip of the iceberg”. In the United States reporting cases to Adult Protection Services is mandatory in many states. This has made the study of the prevalence of elder abuse in the United States easier but does not completely eliminate the effects of poor reporting by victims, carers and staff (Payne & Fletcher, 2005).

Baring this in mind, a large-scale random sample study of people living in the United States suggested that elder abuse, including physical abuse, verbal abuse and neglect, affects 3.2% of the population (Pillemer & Finkelh, 1988). Similarly, elder abuse including financial, physical, emotional abuse and neglect was found to affect 4% of the Canadian population (Podnieks, 1992) and 5.8% of the Dutch population (Comijs, Penninx, Knipscheer & van Tilberg, 1999). Further, elder abuse including all the types described above as well as theft, was found to affect 8% of the population in Denmark and Sweden (Tornstam, 1989). Unfortunately, there are no figures on the prevalence of elder abuse in different cultural and social groups. Given that none of these studies include all the different types of abuse included in the British definition, it seems appropriate to assume that a prevalence study in Britain would return a much higher rate of occurrence.

2 Theories designed to explain elder abuse

Having reviewed the definition of elder abuse and its prevalence we move on to theories that researchers have devised to explain it and that clinical psychologists might use in their work with instances of suspected or actual abuse. These include the theories of Caregiver Stress, Trans-generational Violence, Social Exchange, Psychopathology of the Caregiver, Social Isolation and Double directional Violence.
2.1 Caregiver Stress Theory
Evidence suggesting that victims of abuse tend to be physically and/or mentally dependent on their caregivers (Eastman, 1994) has lead theorists to hypothesise that abuse occurs when carers experience stress as a result of caring for an older adult with insufficient resources and support. This theory is applicable to elder abuse that occurs in the community or in care settings. Although it continues to be very popular, researchers have struggled to support it. Research looking specifically at the risk factors associated with elder abuse has found that the caregiver stress and care-receiver dependence factors, implicit in the caregiver stress theory, are not dominant risk factors for elder abuse (Pillemer & Finkelhor, 1988; Homer & Gilford, 1990). This seems to throw the whole theory of caregiver stress into question. Then again, dementia continues to be associated with abuse (Dyer, Pavlik, Murphy, Hyman, 2002) and researchers continue to suggest that this is because many dementia sufferers exhibit disruptive and aggressive behaviours which are a major cause of distress and stress for carers.

2.2 The Trans-generational Violence Theory
The trans-generational violence model of elder abuse originates from the field of child protection where the concept of dangerous families has been used to describe families where violence has become a normal way of coping with change (Dale, 1987). There is evidence to suggest that children who are abused by their parents internalise violent behaviour through social learning and that a significant proportion then turn violent towards their own children and spouses (Hotaling & Sugarman, 1986). On the basis of this evidence, theorists have hypothesised that these children also become violent towards their parents once the dependency roles shift from child to parent. Unfortunately, there is a lot of evidence for this theory in the literature on family violence but none in the literature on elder abuse (Ogg & Munn-Giddings, 1993). Those that have looked specifically at this issue have pointed out that although abused children may have learned to be violent, not all of them are violent towards their parents and those that are violent towards their parents may be settling old scores rather than exhibiting a learned behaviour (Wolf & Pillemer, 1989).
2.3 The Social Exchange Theory
The Social Exchange theory suggests that people choose to enter into and maintain relationships because of the reciprocal exchange of rewards and responsibilities that they offer. Relationships with an imbalance in the exchange of rewards and responsibilities are often ended because one person is not benefiting from the exchange. Relationships between older adults and their carers often have an imbalance in the exchange of rewards and responsibilities because older adults that are dependent and have a low social status have less to offer. Yet older adults and carers are unlikely to end an unjust relationship because of the older adult’s dependence. It has been suggested that in some situations unjust relationships of this sort become abusive (Wilber & McNeilly, 2001).

In contrast with the assumptions of social exchange theory, evidence exists to suggest that in the community abusive caregivers are often more dependent than those they care for, (Pillemer & Finkelhor, 1988; Homer & Gilleard, 1990). On the other hand Nelson (2000) points out that social exchange theory can accurately explain the occurrence of abuse in care settings since the asymmetrical structure of dependence and control between staff and patients in these settings is inevitable. This suggests that although this theory may not always be applicable to instances of abuse in the community it remains a viable way of explaining abuse in care settings.

2.4 The Psychopathology of the Caregiver
The Psychopathology of the caregiver theory is based on evidence that suggests that rates of substance abuse, mental illness and learning disability are particularly high amongst abusive caregivers (Homer & Gilleard, 1990; Wolf & Pillemer, 1989). It have even been suggested that some abusers may represent a population that would previously have been institutionalised (Quinn & Tomita, 1997). This puts into question the theory of caregiver stress and reverses the dynamics suggested by the social exchange theory at least in relation to abuse that takes place within families.

Critics of this theory point out that since other factors such as race, socio-economic background, gender, poverty and access to resources have not been taken into account it is difficult to say that the psychopathology of the carer is the cause of the abuse. They also point out that this theory was put forwards to explain child abuse but has now been
abandoned (Ogg & Munn-Giddings, 1993). On the other hand we are reminded again and again not to compare elder abuse to other forms of abuse so it may be too early to dismiss this theory.

**2.5 Social Isolation**

As with many other forms of abuse, social isolation is a common feature of elder abuse. Some have suggested that it may be a causal factor. They argue that individuals with strong social networks have the support necessary to prevent abuse occurring. However, is social isolation enough to cause elder abuse? Researchers have found that abused elders are more likely to live with the abuser and at least one other person (Homer & Gilleard, 1990; Pillemer & Finkelhor, 1988). At the very least, this suggests that abused elders do not appear to be social isolated. Interestingly, it seems abused elders are more likely to perceive that they have low social support (Lachs & Pillemer, 2004). This suggests that although abused elders may not appear to be socially isolated they may feel socially isolated. Older adults are unlikely to feel supported by the people who abuse them and abusers are known to slowly cut the person they’re abusing off from their friends and family (Quinn, 2000). Thus, it seems older adults’ sense of social isolation may be a symptom of abuse rather than a cause.

**2.6 Double-directional violence**

Research has shown that carer violence is associated with violence on the part of the care receiver (Steinmetz, 1988; Homer & Gilleard, 1990). This has lead to a theory that suggests that both the carer and the care receiver have a part to play in the occurrence of abuse. This fits with what we know about the abuse of dementia sufferers (Dryer, Pavlik, Murphy and Hyman, 2002). Steinmetz’s research suggests that most of the overt violence is perpetrated by the care receiver. Some have suggested that parent child dyads may be reliving conflicts that originated in adolescence (Giordano & Giordano, 1984). Homer & Gilleard found that abusive dyads were more likely to have had a poor pre-morbid relationship. On the other hand, other studies have found no difference between the interpersonal conflict experienced by abusive dyads and non-abusive dyads (Suiter & Pillemer, 1988).
In summary, although none of the theories we have described can account for the multi-faceted nature of elder abuse single-handedly, they may all have something to contribute to our understanding of it. Having established what is currently known about elder abuse, in the following section we shall discuss the practices that may be helpful to clinical psychologists working with cases of suspected abuse.

3 Practices helpful to psychologists when abuse is suspected

Establishing whether elder abuse has occurred and obtaining an accurate account of events when abuse is suspected is important for criminal proceedings and for therapeutic work. It means the abuse can be brought to an end, prevented from occurring again and allows the consequences to be addressed transparently. In the following sections we will describe the psychological practices psychologists can use to ensure abuse is reported, recognised and accurately recorded.

3.1 Ensuring it is reported

3.1.1 Being informed and vigilant

As we have seen victims and care-workers that could report instances of abuse rarely do (Richardson, Kitchen and Livingston, 2002; Homer & Gilzeard, 1990). One reason for this may be that they lack appropriate information about the definition of elder abuse. Elder abuse has not had a lot of media coverage so they may simply not be familiar with the issue and its different guises. They may also perceive events that would be considered abusive in a different way. Some older adults may think they are partly responsible for the abuse. Others may not consider something abusive because they attribute it to a particular cultural tradition. Moon (2000) found differences in the way abusive scenarios were interpreted by people from different cultural groups. These differences could be attributed to diverse cultural traditions and to people's level of western acculturation. Victims and care-workers may also not report instances abuse if they are unsure about the procedures used by health and social services to address it. Victims may be afraid of the consequences for themselves and their abuser. Care-workers may be afraid of the consequences for their relationship with other clients, staff and families.
Clinical psychologists, who have a professional responsibility to be familiar with current literature on elder abuse and NHS policies and procedures, are well placed for sharing this information with clients and care-workers (Division of Clinical Psychology (DCP), 1995). They can help carers and care-workers maintain a clear understanding of their legal responsibilities and victims maintain a clear understanding of their rights. They can give victims a realistic idea of the potential consequences of reporting abuse. Clinical psychologists should also be well placed for understanding different perceptions of abusive situations. They strive to work collaboratively with their clients to develop an understanding of their situation. This is generally referred to as the process of formulation, which is achieved by developing a number of hypotheses based on psychological theories and then testing them out with clients (DCP, 2001). Moon (2000) and others suggest that understanding differences in people’s perception of abusive relationships is an essential part of recognising elder abuse, choosing the right intervention and achieving successful outcomes (Wilber & McNeilly, 2001).

3.1.2 Providing a ‘safe space’ for disclosure

Research indicates that abusive carers and some victims are more likely to report abuse when they have been given a ‘safe space’ in which to do so. This ‘safe space’ consists of an interaction with a person who is genuine, empathic and non-judgmental (Brandl, 2000; Lachs & Pillemer, 2004; Marriott, 1997; Homer & Gilleard, 1990). Although disclosures of information that may be used in criminal proceedings should be referred to the police (DoH and HO, 2000), clinical psychologists may find that individuals disclose to them because they provide a ‘safe space’ in which to do so with their basic counselling skills. These include being genuine, warm and empathic. Psychologists use these skills to develop a therapeutic rapport with the client because they perceive this to be an important agent of therapeutic change (Rogers, 1957).

3.2 Ensuring it is recognised

3.2.1 By the clinician

Marriott (1997) suggests that even when abuse has been reported clinicians’ own psychological processes may prevent abuse from being recognised. She suggests that their attitudes and beliefs about elder abuse based on previous experiences may influence their vigilance for signs of abuse and the way they use definitions and guidelines related to
elder abuse. She also describes how their relationships with families and staff groups and their perceptions of the rules governing these systems could prevent them from seeing the abuse in isolation and correctly identifying it. She refers to the theory of cognitive dissonance to explain how this might happen. This theory describes the unwanted feeling we experience when we perceive inconsistencies between our perceptions, attitudes or behaviour. When this happens we usually try to re-establish consistency by changing some aspect of the perception or experience. Marriott points out that clinicians may get a feeling of inconsistency if the reality of abuse clashes with their existing perception of a family or care setting. In this situation she hypothesises that clinicians might re-create a feeling of consistency by refusing to believe that the abuse took place. This could lead to instances of abuse being left unrecognised.

Yet clinical psychologists are actually likely to escape these pitfalls since they strive to maintain an awareness of their pre-conceptions and psychological processes. They do this through reflection, supervision and multi-disciplinary team working (DCP, 1995, 2001). Psychologists use self-reflection to maintain an awareness of their thoughts, feelings and behaviours during therapeutic work. They do this in an effort to maintain a non-judgmental stance towards their clients. Psychologists also reflect on their psychological processes in discussions with other professionals. They might discuss them in peer supervision or with other professionals in a multi-disciplinary team. Sharing these thoughts, feelings and behaviours with other professionals, getting feedback on them from other professionals and reflecting on them with other professionals allows pre-conceptions and psychological processes to be brought into consciousness (Marriott, 1997).

3.2.2 By the team

On the other hand it seems multi-disciplinary teams can also be influenced by the psychological processes of the group and its members. Current National Service Framework (DoH, 2001) guidelines suggest that multi-disciplinary teams adopt a single assessment process. This means that one or two professionals assess new referrals and report their findings to the rest of the team. If the professionals who have carried the assessment do not believe that abuse has occurred because of the processes or pre-conceptions described above they might fail to report any concerns to the rest of the team.
Marriott (1997) also highlights how group processes in a multi-disciplinary team could prevent abuse from being recognised. She refers to social impact theory, which suggests that individuals in a large group make less effort than if they had worked alone. Hence individuals in a team discussing a case of suspected elder abuse may make less effort to argue for the recognition of elder abuse if they perceive the burden and responsibility for risk to be shared. Marriott goes on to suggest that working in groups might also prevent abuse from being recognised because it has the effect of polarizing decisions, which can result in a shift in opinion either to a more cautious opinion or a more risky opinion. She points out how in some cases this can result in groups ignoring clear evidence against a decision.

Psychologists may be able to prevent teams from falling into these traps because of their understanding of group processes based on their extensive experience of group work with clients (DCP, 1995). They may be able to suggest safeguards such as the use of a reflective team. Reflecting teams are used in Systemic Therapy to observe the group in action and make observations about the group dynamics without being critical or judgemental. In this way they help bring group dynamics into the group’s consciousness (Anderson, 1987). This would mean processes like those described above could be avoided. In line with this measure, psychologists might also suggest that other individuals such as the victim, abuser and/or family are invited to team meetings to preserve the variety of viewpoints.

3.3 Getting the facts

3.3.1 Assessment skills

Professionals working in this area have a legal responsibility to record any information that relates to abuse as accurately and objectively as possible (DoH and HO, 2000). Marriott (1997) suggests that psychologists can contribute to this by using structured assessment protocols including those that inform behavioural analyses. Behavioural assessments structure the event into potential causes and effects and avoid reference to the thought and feelings of those involved. This can be useful when cognitive and emotional factors are in danger of taking over and overwhelming the process of information gathering.
Establishing the reliability of the victim’s account by assessing their cognitive functioning could be another aspect of a psychologist’s role in establishing an accurate version of events. Older adults can have varying degrees of cognitive impairment, which could affect their recollection and/or interpretation of events. A cognitive assessment might also contribute to an assessment of a person’s capacity to consent. This could be useful in criminal proceedings and in the interest of understanding the role different individuals play in an abusive interaction (DCP, 2001). In cases where the victim’s level of impairment means that their account is unreliable, liaising with other professionals to get as much information as possible about a client, their family or a nursing home is essential (Wilber & McNeilly, 2001).

3.3.2 Recording skills
Another aspect of obtaining an accurate account of abuse is the recording process. Brandl (2000) suggests that keeping records that accurately reflect the account of events contributes to the empowerment of the victim. She reminds us that these records can be used in criminal proceedings and that records that contain opinions could be used to cast doubt on the validity of the victim’s testimony. Psychologists have a professional responsibility to record information in a clear and objective manner (DCP, 1995).

In summary it seems psychologists have a number of practices at their disposal to ensure elder abuse is reported by clients and care-workers, recognised by services and accurately recorded. In the following section we shall examine the practices and models at their disposal to ensure that cases of actual abuse are adequately managed.

4 Practices helpful to psychologists when abuse has occurred
Once the occurrence of elder abuse has been established, recognised and reported clinicians can proceed in planning an appropriate intervention. This requires an understanding of how the abuse came about based on the views of all those involved as well as multi-disciplinary perspectives. In the following section we shall describe how this multi-agency and multi-disciplinary formulation can be achieved.
4.1 Planning the intervention

4.1.1 Formulation

The intervention should be based on an understanding of how the abuse came about through collaborative formulation. Working collaboratively with clients ensures that the formulation accurately reflects the experience of the people involved in the abusive relationship. An intervention designed on the basis of such a formulation should be more effective (DCP, 2001).

However, there is a risk of formulations being unrepresentative of clients' experiences, especially when they are based on a limited number of psychological theories. Psychologists can feel pressured into making the client's experiences 'fit' with a particular model. Formulations that draw on numerous theories and that are repeatedly revisited and adjusted in collaboration with as many members of the abusive system as possible are more likely to represent the clients' perspectives.

4.1.2 Multi-disciplinary team working

Clinical psychologists could also base their formulation on the biopsychosocial model in an effort to take different perspectives of the abusive event into account. This model was developed by Engel (1977) as a response to the biomedical model, which dominated health care provision for many years. He argued that it is essential to take account of biological, psychological and social factors to achieve an accurate formulation and choose an appropriate intervention. This model promotes an inter-disciplinary approach to formulation and intervention, which is recommended by the Department of Health (DoH, 2000) and other authorities on abuse (Wolf & Pillemer, 1989; Marriott, 1997).

4.2 Interventions

Once the multi-disciplinary team and those involved in the abusive situation have agreed on a formulation they can choose the interventions they feel will be most appropriate and effective. Since interventions should be based on a formulation that is unique to a particular case, it will not be possible to describe a standard psychological intervention for elder abuse. The different interventions I suggest the clinical psychologists might use could be used in combination with one another. These include psycho-social
interventions, cognitive-behavioural interventions, psychodynamic interventions and systemic interventions.

4.2.1 Psycho-social interventions
Psychosocial interventions could be used with the victim, the abuser, the family or the staff team. They include things like providing education, advocacy, mediation and support. Education about particular conditions and the effects these conditions will have on a person’s behaviour could be useful for carers and care-workers who experience carer stress and victims whose abusers have mental health or substance abuse problems (Anme, 2004). Education could also reduce the risk of ageism affecting the care an older adult receives from family or staff team (Giordano & Giordano, 1984). Advocacy has been described as an important way of redressing the power imbalance between older adults and care-workers that increases the likelihood of abuse (Nelson, 2000). It could also help ensure that the needs of older adults are understood and taken into account by families and staff teams in care settings. Advocacy could also be part of a more general mediation role for a clinical psychologist working with a family or staff team (Johnson, 2000). Lastly, support could take the form of reducing a victim’s social isolation by developing a therapeutic rapport with them or referring them to a day centre (Brandl, 2000).

4.2.2 Cognitive and behavioural interventions
Cognitive-behavioural interventions could be used to help victims recover from some of the potential psychological consequences of abuse. Cognitive-behavioural interventions could also be used with carers who suffer from certain mental health problems. Cognitive-behaviour therapy has been found to be an effective treatment for depression and anxiety in older adults (Arean & Cook, 2002; Stanley et al., 2003). Cognitive interventions, such as Motivational Interviewing could be used to help carers recover from addictions (Miller, Rollnick & Conforti, 2002). Other cognitive interventions could be used to help the abuser find more effective ways of managing stress and anger (Novaco, 1975). Behavioural interventions could be used to reduce carer stress by helping families and staff teams manage an older adult’s disruptive behaviour (Homer & Gilleard, 1990).
4.2.3 Psychodynamic interventions
Psychodynamic interventions could be used to help the victim or the carer understand deep-rooted family issues that have lead to abusive interactions between the caregiver and the care-receiver. This could involve the abuser coming to terms with having been abused as a child or resolving filial crises (Dale, 1987; Giordano & Giordano, 1984). The psychodynamic principles of transference or counter-transference (Lemma, 2003) could also be taught to staff or family members to help them understand the difficult communications that can occur between a carer and care receiver (Richardson, Kitchen & Livingston, 2002).

4.2.4 Systemic interventions
Systemic interventions could be used to help victims, carers, families and staff teams resolve the problematic system dynamics that lead to abusive behaviour. With this approach all members of the system would develop a better understanding of each other’s views and possibly change their views as a result of being exposed to different perspectives (Edinberg, 1986). This approach can be used with individuals and groups.

In conclusion therefore, it seems clinical psychologists have many theories, models and practices at their disposal when working with instances of suspected and/or actual abuse. These tools can help them ensure that instances of elder abuse are reported by victims and carers, recognised by services and accurately recorded for investigations. They can also help psychologists ensure that instances of elder abuse are adequately understood and appropriately addressed. Nevertheless, psychologists and others working with instances of elder abuse would greatly benefit from further research on the prevalence and dynamics of elder abuse in the community, in care settings and in different cultural and social groups. Writing this essay has helped me to understand the multi-faceted nature of elder abuse and recognise the multiple ways in which clinical psychologists can be involved in promoting the issue and ensuring its adequate management. I believe that in depth discussions about the role of clinical psychologists in specific areas like this could be hugely beneficial to the profession.
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Summary of Adult Mental Health Case Report

1 Title
Behavioural Management of a 35-year-old Somali woman with Bipolar Disorder

2 Referral and Presenting Problem
Aliyah was a 35-year-old Somali woman diagnosed with Bipolar Disorder (BD). At the time of referral, she was going through a depressive episode. This meant she felt extremely low and had no motivation to go out or participate in the upbringing of her children or the upkeep of her home. Her Care Coordinator (CC) referred her to psychology for support in managing this episode. However, Aliyah’s depression seemed to lift as the intervention began which meant that the intervention focused more on relapse prevention.

3 Background
Aliyah had been traumatised by her experience of the Somali civil war and had developed BD in Europe several years later after a significant life event. She went on to have three periods of depression shortly followed by mania after experiencing stressful life events. She was hospitalised on each occasion because she had a tendency to become violent when manic and suicidal when depressed. Her sister had also developed BD.

4 Formulation
Aliyah may have had a biological vulnerability to BD that was exacerbated by her experience of the Somali civil war. This has been associated with circadian rhythm sensitivity to changes in daily routines. Aliyah be have been sensitive to stressors because they disrupted her routines and consequently disrupted her circadian rhythms. These disrupted rhythms are thought to provoke prodromal symptoms of BD rather than acute episodes. It is the way the BD sufferer manages these symptoms that is thought to determine whether they develop into acute symptoms.

5 Intervention
The first part of the intervention included psycho-education about BD, the role of stress and the relationship between environment, mood and behaviour. The second part
involved the identification of Aliyah's relapse signatures and the development of relapse drills including effective coping strategies for managing prodromal symptoms. The third part comprised of teaching Aliyah relaxation techniques to use in the prodromal phases of a manic episode. The fourth part involved the development of an activity schedule to encourage the establishment and maintenance of stable routines during prodromal phases.

6 Outcome
The time frame within which this intervention took place meant that an evaluation of Aliyah's use of the relapse drills could not be carried out. Nevertheless, she demonstrated an improved understanding of her experience of BD and a good understanding of how the relapse drills might help her to avoid acute episodes.
Summary of People with Learning Disabilities Case Report

1 Title
Systemic work with the staff team of a supported accommodation facility implementing a photo program with a 29-year-old deaf and autistic woman

2 Referral and Presenting Problem
Laura was a 29-year-old profoundly deaf woman of White-Asian decent with autism and moderate to severe learning disabilities. She was exhibiting distressed and repetitive behaviours, which were difficult for staff at her group home to manage or understand. Her key-worker referred her to psychology for advice on how to manage her.

3 Background
At an early age, Laura was sent to a boarding school for deaf children in Manchester. She returned to live with her family when she was nineteen and soon began to 'cling' to her mother. This meant that she restricted her mother’s movements and prevented her from interacting with the rest of the family. This resulted in a number of family crises and eventually Laura was placed in supported accommodation. Laura found the transition difficult but eventually settled in, preferring it to her own family home.

4 Circumstances at the time of referral
Laura attended a day centre four days a week but did not have a set routine on other days. She ‘clung’ to her key-worker in the same way as she had clung to her mother. This prevented her key-worker from working with other clients as well doing other duties. Laura also exhibited repetitive behaviours such as repeatedly asking for her medication after meals and standing by the door with her coat on as other residents left to go to the day centre on days when she did not. The psychologist who screened the case was impressed with the methods some staff were using to manage these behaviours and advised them to develop guidelines so that the team could be consistent in their approach. They had still not done this at the time of intervention several months later.
5 **Formulation**
Laura’s multiple disabilities suggested that she had access to little information about the world around her and little understanding of any information she got. They also suggested that she preferred to follow set routines and that not having set routines caused her a great deal of anxiety. Furthermore, it is likely that they caused her to have few resources with which to manage her anxiety. Laura’s life experiences are likely to have caused her to develop an insecure attachment style. In this case it seemed as if she lived in perpetual fear that the people she cared for would abandon her. Laura seemed to try to manage her anxieties by trying to control those around her through her ‘clinging’ behaviour and repetitive demands.

6 **Intervention**
Laura had also been referred to Speech and Language and Occupational Therapy. This resulted in the development of a photo program aimed at improving communication between her and staff at the group home. This would also promote the development of a set routine. This seemed an appropriate way of alleviating many of Laura’s anxieties. However the Speech and Language and Occupational therapists were concerned about the staff team’s motivation to implement the photo program. This resulted in a decision to carry out a systemic piece of work with the staff aimed at promoting the use of the photo program. This involved a series of consultations with staff about their understanding of Laura’s difficulties and the impact of using the photo program. I took a neutral and curious stance throughout and avoided taking the position of ‘expert’ in order to promote a collaborative process of exploration.

7 **Outcome**
Staff were able to make a number of decisions about how to implement the program during the consultations. However they also found it difficult to commit to maintaining the program during busy times such as when a new client would be admitted or when they were understaffed. This highlighted a number of issues that were likely to impact on Laura. The staff had little understanding of autism or of behaviour theory. This meant they found it difficult to comprehend the importance of having a structured activity schedule or a consistent approach. In addition they felt undervalued and unsupported by higher management who were putting pressure on them to fill beds whilst limiting their
resources. This resulted in them being less motivated to understand and address Laura’s difficulties. Their attempts to do this by referring her to the Community learning Disabilities Team (CLDT) only exacerbated this as the CLDT encouraged them to use more resources to support her.
Summary of Children and Adolescents Case Report

1 Title
Cognitive behaviour therapy with a 16-year-old girl with obsessive-compulsive disorder

2 Referral and Presenting Problem
Joanna was a 16-year-old white British female from a working class background referred by her GP because she had developed an obsession with contamination and was experiencing intrusive violent thoughts. This was causing her distress, which she was managing with a series of compulsive behaviours.

3 Background
Joanna originally experienced an obsession with contamination and intrusive violent thoughts when she was seven-years-old. She managed the distress they caused her with the same compulsions she was using at the time of referral. Three concurrent experiences seem significant: her father’s admission to hospital for an operation because he was suffering from Crohn’s disease, a difficult transition from primary to junior school and her anxiety at having to have additional tuition for her first holy communion. On this occasion, Joanna started exhibiting symptoms when she was fifteen-years-old and in the process of preparing for her GCSE’s. She recalled being very anxious about her exams and worrying that something unexpected would happen to make her fail. It also seems relevant that her father became alcoholic following his operation, had received support from Alcoholics Anonymous and was in remission at the time of the intervention.

4 Formulation
Joanna’s presentation suggested that she had developed cognitive schemata that involved catastrophising or in other words future-oriented thoughts that involved predictions of danger about her and her family. Her fears about losing her family through illness or attack may have been related to a fear of being abandoned by them. This may have developed as a result of early life experiences such as her parents not being available to her when her father was sick with Crohn’s disease. Joanna may have developed compulsions around this time in an effort to cope with her anxiety levels. The fact that her OCD symptoms resolved for a few years might be evidence for the fact that her
cognitive schemata became latent when family circumstances returned to normal. They may have re-emerged when her father was once again pre-occupied with recovering from alcoholism in the context of her sitting GCSEs.

5 Intervention
A cognitive behavioural therapy program designed specifically for children and adolescents was followed. This included psycho-education about the neuro-behavioural model of OCD and of the epidemiology and phenomenology of OCD to normalise Joanna's experience; externalising OCD to help Joanna reframe it as something that she had a choice about including or excluding from her life; training in constructive self-talk to help her replace maladaptive cognitions with realistic statements that highlighted her ability to cope with the fear-provoking situations; training in cognitive restructuring which involves Joanna confronting the erroneous assumptions underlying her catastrophic estimations of danger and perceived responsibility; cultivating nonattachment to OCD which involves supporting Joanna to develop self-talk statements to remind her that she did not have to address episodes of anxiety; mapping which required Joanna to give a detailed account of her obsessive thoughts and compulsions and exposure and response prevention exercises to allow Joanna to experience anxiety without carrying out compulsions and learn that her obsessions did not imply an increased risk of the feared event happening.

6 Outcome
Joanna reported having fewer violent intrusive thoughts, fewer occasions of hand washing and an increased willingness to let others touch things she had touched. Joanna’s parents also reported that Joanna was more willing to share cutlery, crockery and food with them. Generally Joanna seemed confident in her ability to beat OCD. Joanna was also more confident about asking her parents for support and asserting herself in their presence.
Summary of Older Adults Case Report

1 Title
Neuropsychological assessment of a 75-year-old man with Parkinson’s disease, cognitive deterioration and hallucinations.

2 Referral and presenting problem
Mr Smith was a 75-year-old gentleman with Parkinson’s disease referred for a neuropsychological assessment to determine whether the sudden cognitive deterioration and hallucinations he had been experiencing had organic, functional or pharmacological origins. The results would contribute to an assessment of his capacity to live independently and to a new care plan.

3 Background
Mr Smith was a working class man who had spent most of his life working in the catering and service industries. He says he had a happy childhood but didn’t always like school and especially not arithmetic. He was right handed and wore glasses.

4 Presentation
Mr Smith had recently become a widower at the time of assessment. He told me that he missed his wife very much and had been feeling quite hopeless about the future. He said that he had been finding it difficult to go back to sleep after waking at 3 or 5am. He said he would often think about the life he used to lead with his second wife. He said that he occasionally felt depressed and tearful but did not feel helpless. He said he had had a few thoughts about committing suicide, but had not made any plans and did not have any intentions of hurting himself.

5 Family Views
His stepchildren were concerned that he wasn’t managing his medication effectively. They said his wife, their mother, used to manage this for him. His stepson’s partner, who is a doctor, reported that he had been taking double his normal dose of anti-Parkinson’s medication. His family were also concerned that he had lost a lot of weight.
6 **Medical History**

Mr Smith suffered from Parkinson's disease and Hypertension. He exhibited physical signs of Parkinson's disease such as bradykinesia, an expressionless face, a festinant gait, cogwheel rigidity and lead pipe rigidity. A CT scan of his brain revealed mild prominence of the ventricles with evidence of generalised age related involutional change. There was no evidence of a haemorrhage or lesion. Mr Smith denied any family history Parkinson's disease, Huntingdon's disease, dementia or any psychiatric disorder. He did not drink, smoke or take illicit substances.

7 **Hypotheses based on literature**

Hypothesis 1: Mr Smith was suffering from severe cognitive dysfunction as a result of Parkinson's disease. This means he was unable to manage his medication independently and experienced hallucinations as a result of taking an overdose. He should have demonstrated poor executive function, poor immediate verbal memory, preserved delayed and recognition verbal memory, poor verbal fluency and poor visuospatial skills.

Hypothesis 2: Mr Smith was suffering from acute Depression following his wife's death. This was affecting his ability to manage his medication independently so he had accidentally taken an overdose and had experienced hallucinations as a result. He should have demonstrated poor attention and concentration and show signs of clinical depression.

Hypothesis 3: Mr Smith had Dementia with Lewy bodies. This was causing him to have severe cognitive impairments and visual hallucinations. If this was the case he should have demonstrated fluctuating cognitive impairments and poor attention and alertness.

Hypothesis 4: Mr Smith had Alzheimer's. This was causing him to have severe cognitive dysfunction. This means he was unable to manage his medication independently and had experienced hallucinations as a result of taking an overdose. If this was the case he should have demonstrated preserved remote memory, impaired immediate verbal memory, impaired recognition memory, severely impaired delayed memory, poor
naming ability, poor executive function and poor verbal fluency with worse semantic fluency than phonetic fluency.

8 Assessment procedure
The neuropsychological battery Mr Smith completed includes:

- The National Adult Reading Test (NART)
- The Wechsler Adult Intelligence Test III (WAIS-III Short Form):
  - Vocabulary
  - Picture Completion
  - Similarities
  - Arithmetic
  - Digit Span
  - Information
  - Letter-number sequencing
  - Matrix Reasoning
- Logical Memory I & II from the Wechsler Memory Scale III (WMS-III)
- The Doors Test from Doors & People
- The Controlled Oral Word Association test (COWA)
- The Hamilton Depression Scale (HDS)
- The Hospital Anxiety & Depression Scale (HADS)

This battery assessed pre-morbid intellectual functioning, verbal intellectual functioning, verbal comprehension, perceptual organisation, working memory, immediate auditory verbal memory, delayed auditory verbal memory, visual recognition memory, letter fluency, category fluency, depression and anxiety.

9 Results of assessment
Results suggested that Mr Smith was experiencing cognitive impairment as a result of having Parkinson’s with dementia and that this was causing him to mismanage his medication, resulting in hallucinations. However there was potentially too little information and too many confounding variables for a diagnosis to be made on the basis of this assessment. Further information about when Mr Smith first developed
Parkinson's disease and his level of cognitive functioning since that time would have been helpful. In addition, a neuropsychological assessment carried out when Mr Smith had not experienced a recent life event may have provided a more valid measure of his abilities.
Summary of Elective Placement Case Report

1 Title
Narrative therapy with a 69-year-old woman with depression

2 Referral and presenting problem
Rose was a 69-year-old Caucasian, Irish woman. She was referred to her local Community Mental Health Team (CMHT) by her General Practitioner (GP) when she reported that the depression she had lived with for many years had got worse since the break-up of her marriage.

3 Background
Rose was born in 1936 in rural Ireland. She was the youngest of six and her parents’ only daughter. Rose’s father left her mother when Rose was very young. Since Rose’s mother did not work, the family fell into extreme poverty. Rose’s mother then died when Rose was eleven, leaving the children to fend for themselves. Most of Rose’s brothers left to find work at this point but did not send money home. Those that stayed fought amongst themselves and beat Rose. They did not care for her or provide for her. Rose and her brothers were shunned by the local community and several men made attempts to molest Rose as she grew up.

Rose started working as child minder at the age of fourteen. She was regularly beaten or sacked for not being able to keep up with her employers’ demands. She decided to take a job in London when she was sixteen. There she worked as a maid and in a factory. She was often discriminated against for her nationality and became very untrusting and cold towards others. Conversely she became flirtatious towards men she met at dances. She met her husband at one such dance.

Rose became mentally unwell when she had her first child. She had complications and struggled to care for the baby without any support from her husband and his family. Rose became clinically depressed and had thoughts of harming her child. At first she was prescribed medication but a year later she was hospitalised and given ECT. Rose had a second child and being a mother gave her something to live for. Her husband paid her
and the children no interest and spent his earnings on sporadic binge drinking sessions. Rose had to get a job to support the family.

Rose and her husband retired at sixty when their children had left home and got married. Rose took on the role of grandmother gladly. Her husband then left her without warning, taking their life savings. Rose’s son then moved to Ireland with his family. This made her very sad as she had no other grandchildren. She felt as though she had lost her purpose in life. She was now also very isolated.

4 Formulation
At a young age Rose learned that she was not worthy of love or respect and that her purpose in life was to be a wife and a mother that always put others’ needs before her own. She later learned that she could get love and respect from taking on those roles. Unfortunately, she lost those roles when her children grew up and moved away and when her husband left her. This triggered an identity crisis and unresolved feelings about being worthless. Rose tried to maintain the status quo by continuing to put her friends and family first but they took this for granted. This left Rose feeling used, unloved and hopeless about the future.

5 Intervention
Rose seemed keen to tell her life story and believed that the process of off-loading might help ease the burden of her depression. In addition she had adopted a medical understanding of her depression which made her feel abnormal. As such, a narrative approach to therapy seemed appropriate since it involves the telling and re-telling of stories, views problems as separate to people and encourages the development of an adaptive narrative. Consequently I planned to support Rose to find an alternative story that she might want to live her life by and that would not support the problem of her feeling worthless. It would also involve deconstruction conversations in which the cultural contexts that gave rise to and maintained Rose’s problems would be explored. I also planned for Rose and I to trace the history of her problems in order to identify inconsistencies that might lead to alternative stories also called unique outcomes. This would then allows to have conversations in which Rose’s chosen alternative story could be thickened for her to adopt it more easily. Lastly I planned to manage the therapeutic
relationship between Rose and I to form the basis for an alternative story about Rose as an interesting and valued person.

6 Outcome
Rose said she was having fewer bad days. She also said she had not had feelings of derealisation or any thoughts about dropping dead since we had started meeting. Overall she felt lighter from having unburdened herself. She still had the occasional bad day but was beginning to see how she might be able to have more agency in determining whether she had a bad day or not. Rose had also taken steps to increase the amount of social and recreational activities in her life.
Overview of clinical experience gained from placements

Adult Mental Health Placement

Settings: I was placed in a London Community Mental Health Team (CMHT) and had the opportunity to work with clients in their homes, at the team base, in the local acute ward and in a residential home.

Models: I used Cognitive Behavioural, Behavioural, Psycho-educational and integrative approaches to my work.

Range of experience:

- I carried out psychological assessments including cognitive assessments.
- I worked individually with clients with Panic Disorder, Agoraphobia, Somatic Disorder, Bipolar Affective Disorder, Bulimia Nervosa and severe memory impairment.
- I facilitated and co-facilitated educational groups on the inpatient ward on topics such as relapse prevention and healthy living.
- I gave a presentation on the results of a Service Related Research Project I had carried out in the trust.
People with Learning Disabilities Placement

Settings: I was placed in a London Community Learning Disabilities Team (CLDT) where I was given the opportunity to work with clients and carers at the team base, in residential homes, day centres and respite care facilities.

Models: I used Cognitive Behavioural, Behavioural, Solution Focused, Systemic and Psychodynamic frameworks.

Range of experience:
- I took part in multi-disciplinary assessments and psychological assessments, including cognitive assessments.
- I worked with individuals with challenging behaviour including aggression, verbal outbursts, property destruction and repetitive and distressed behaviour.
- I worked with individuals who suffered from Depression and Anxiety in the context of bereavement, compulsive shopping and Dementia.
- I facilitated group sessions with staff at a residential home to support them to implement a communication program for one of their clients.
- I co-facilitated a group for couples with learning disabilities to support them to work through their relationship issues.
- I provided staff at a residential home, respite care facility and a day centre with consultation on how to manage a client who presented with challenging behaviour.
**Children and Adolescents Placement**

**Settings:** I was placed in a London Child and Adolescent Mental Health Service (CAMHS) and my time was spilt between a tier three Locality team and a Looked After Children team.

**Models:** I used Cognitive Behavioural, Neuropsychological, Psychodynamic, Behavioural, Systemic and Narrative techniques.

**Range of experience:**
- I carried out multi-disciplinary assessments and psychological assessments, including cognitive assessments.
- I worked with young people with Obsessive Compulsive Disorder, disruptive and aggressive behaviour, Somatic Disorder and Depression in the context of being fostered.
- I provided consultation to a foster carer looking after a child with disruptive and aggressive behaviour in the context of having a learning disability.
- I co-facilitated a support group for a Social Services Foster Carer Assessment Team.
- I observed a Webster-Stratton parenting class attended by four mothers.
- I gave a presentation on research on the effects of parental divorce to the psychology team.
Older Adults Placement

Settings: My time was split between a London Older Adults Community Mental Health Team and an Outpatient Rehabilitation Clinic for Older Adults. I had the opportunity to work with clients at the team base, at the rehabilitation clinic, in residential homes and in supported accommodation facilities.

Models: I used Behavioural, Neuropsychological, Cognitive Behavioural, Narrative Solution Focused and integrative techniques.

Range of experience:
- I carried out psychological assessments including cognitive assessments.
- I worked with clients with Parkinson’s disease, Depression, Psychotic Depression, Dementia and Depression and Agoraphobia in the context of a Personality Disorder.
- I co-facilitated a group that aimed to support clients with functional mental health problems to think more positively about ageing.
- I gave a presentation on the use of Cognitive Behaviour Therapy with older adults to the Older Adults Psychology Team.
- I gave a presentation on the background of a trainee clinical psychologist to the multi-disciplinary team at the Outpatient Rehabilitation Clinic.
- I gave a presentation on the use of Cognitive Behaviour Therapy with Older Adults who have experienced a fall to the multi-disciplinary team at the Outpatient Rehabilitation Clinic.
Elective Systemic and Organisational Placement

Settings: My time was split between working with a psychologist who managed psychology input to five acute wards and a CMHT. I had the opportunity to work with clients on the acute wards, on a closed ward, at the team base and in their homes.

Models: I used organisational psychology, group therapy, cognitive behavioural therapy and narrative techniques.

Range of experience:

- I carried out psychological assessments.
- I worked with clients with Depression and Health Anxiety.
- I co-facilitated and facilitated teaching sessions for inpatient staff on the use of Cognitive Behavioural techniques with inpatients with Depression and Psychosis.
- I gave a poster presentation to a trust wide professional forum on these teaching sessions.
- I facilitated an inpatient staff reflective practice group.
- I carried out a review of a staff support group.
- I carried out a pilot study of what inpatients mean when they say they want talking therapies.
- I co-facilitated an open discussion group for inpatients that focused on the experience of being an inpatient and having mental health difficulties.
- I co-facilitated and facilitated a creative expression group on a closed ward.
**Elective Children and Adolescents Placement**

**Settings:** My time was split between a tier four service for children who are under twelve and a tier four service for young people who are between twelve and eighteen. I worked with children and young people in their homes, at the team base and in an inpatient setting.

**Models:** I used Cognitive Behavioural, Integrative, Neuropsychological, and Narrative techniques.

**Range of experiences:**
- I carried out multi-disciplinary and psychological assessments including cognitive assessments.
- I worked with clients with Obsessive Compulsive Disorder, Bulimia and Anorexia Nervosa and Oppositional Defiant Disorder.
- I co-facilitated a teaching session on the use of Cognitive Behavioural Therapy to treat Obsessive Compulsive Disorder in children and young people.
## Research Log Checklist

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>X</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Formulating and testing hypotheses and research questions</td>
<td>X</td>
</tr>
<tr>
<td>2</td>
<td>Carrying out a structured literature search using information technology and literature search tools</td>
<td>X</td>
</tr>
<tr>
<td>3</td>
<td>Critically reviewing relevant literature and evaluating research methods</td>
<td>X</td>
</tr>
<tr>
<td>4</td>
<td>Formulating specific research questions</td>
<td>X</td>
</tr>
<tr>
<td>5</td>
<td>Writing brief research proposals</td>
<td>X</td>
</tr>
<tr>
<td>6</td>
<td>Writing detailed research proposals/protocols</td>
<td>X</td>
</tr>
<tr>
<td>7</td>
<td>Considering issues related to ethical practice in research, including issues of diversity, and structuring plans accordingly</td>
<td>X</td>
</tr>
<tr>
<td>8</td>
<td>Obtaining approval from a research ethics committee</td>
<td>X</td>
</tr>
<tr>
<td>9</td>
<td>Obtaining appropriate supervision for research</td>
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<td>10</td>
<td>Obtaining appropriate collaboration for research</td>
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<tr>
<td>11</td>
<td>Collecting data from research participants</td>
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<tr>
<td>12</td>
<td>Choosing appropriate design for research questions</td>
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</tr>
<tr>
<td>13</td>
<td>Writing patient information and consent forms</td>
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<tr>
<td>14</td>
<td>Devising and administering questionnaires</td>
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</tr>
<tr>
<td>15</td>
<td>Negotiating access to study participants in applied NHS settings</td>
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</tr>
<tr>
<td>16</td>
<td>Setting up a data file</td>
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</tr>
<tr>
<td>17</td>
<td>Conducting statistical data analysis using SPSS</td>
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</tr>
<tr>
<td>18</td>
<td>Choosing appropriate statistical analyses</td>
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<td>19</td>
<td>Preparing quantitative data for analysis</td>
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<td>Choosing appropriate quantitative data analysis</td>
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<tr>
<td>21</td>
<td>Summarising results in figures and tables</td>
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<tr>
<td>22</td>
<td>Conducting semi-structured interviews</td>
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<tr>
<td>23</td>
<td>Transcribing and analysing interview data using qualitative methods</td>
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<tr>
<td>24</td>
<td>Choosing appropriate qualitative analyses</td>
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<tr>
<td>25</td>
<td>Interpreting results from quantitative and qualitative data analysis</td>
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<tr>
<td>26</td>
<td>Presenting research findings in a variety of contexts</td>
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<tr>
<td>27</td>
<td>Producing a written report on a research project</td>
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<tr>
<td>28</td>
<td>Defending own research decisions and analyses</td>
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<td>29</td>
<td>Submitting research reports for publication in peer-reviewed journals or edited book</td>
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</tr>
<tr>
<td>30</td>
<td>Applying research findings to clinical practice</td>
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</table>
An audit of treatment pathways for clients with diagnosed or suspected Asperger Syndrome through Community Mental Health Teams.

August 2004

Year 1

The names of participant clients, professionals, teams and NHS trusts have been omitted from this report to preserve anonymity.
Acknowledgments

I would like to thank:

Victoria Senior, my placement supervisor and the managers and psychiatrists of the CMHTs involved in this project for all their help and support.
Abstract

A report published by the National Autistic Society suggests that most individuals with Asperger syndrome (AS) are not having their needs met by social and health services. As a result many have difficulty completing education programs, getting jobs and developing social networks. In addition many develop mental health difficulties end up in the high-risk category for suicide. In response to this five London based CMHTs sought to determine how well they were meeting the needs of this client group and commissioned a file audit for information about diagnoses, presenting problems and service outcomes. The files of 15 clients with diagnosed or suspected AS who came into contact with these teams since June 2002 were examined. In addition Psychiatrists for four of the five teams were interviewed about their views on specialist service provision for adults with AS within the trust, CMHTs ability to cater for their needs and Adult Mental Health Psychiatrists’ ability to understand and diagnose this condition. The results suggest that the sample had high numbers of diagnosable conditions, high levels of need and that 52% of needs were appropriately addressed. The Psychiatrists reported that they do not believe CMHT’s are able to cater for the needs of this client group and that they lack confidence in their ability to diagnose and understand this condition. A discussion focuses on the importance of exposure and training for good quality service provision and on the problematic definition of appropriate outcome and met needs in this study.
1 Introduction

Asperger syndrome (AS) is a condition believed by some to feature on the Autistic Spectrum. It is similar to Autism but does not feature a general delay or retardation in language or in cognitive development and is associated with an IQ in the more normal range (Wing, 1997). As such individuals with AS can be high functioning but have difficulties with communication, social interaction and imagination which can impact on their day-to-day life and ability to live independently.

There are various estimates of prevalence for AS but one study suggests that it occurs in 1 in 300 people in the UK and more often in males than in females (Ehlers and Gilberg, 1993). Individuals with AS who come into contact with social or health services do so for a variety of reasons. Their needs have been identified by seventeen UK local and national autistic spectrum disorder research projects between 1995 and 2002 and are reported by The National Autistic Society (Powell, 2001). They include diagnosis, support in finding appropriate housing, support in finding appropriate employment, treatment for mental health difficulties and interventions to promote independent living and to prevent social isolation.

Without appropriate support people with AS are at risk of dropping out of school or college, being unable to work, becoming socially isolated and suffering mental health problems (Howlin, 1997). Research has shown that adults with AS are at significant risk of developing affective disorders (Wing, 1981) and that they fit into the 'high risk of suicide' category (Wolf and McGuire, 1995). In 1999 Shah (as cited in Powell, 2001) found that lack of appropriate support for those who are experiencing difficulties can also result in police involvement, prison sentences, admission to psychiatric units and trial and error drug treatments.
At present, although the government specifically excludes people with AS from the group they define as learning disabled they state that: “Adults with Asperger’s Syndrome or High Functioning Autism are not precluded learning disabilities services, and may, where appropriate require an assessment of their social functioning and social skills in order to establish their level of need” (DoH, 2001pg 2). At the same time in the Specialised Services National Definition No22 which describes planned specialised mental health services for adults, the government states that the majority of people with AS and mental health problems should have their “ordinary health and social care needs met by local services” and that only a small number of these individuals would need specialised care services (DoH, 2002, pg 16). This suggests that adults with AS who do not suffer from mental health problems should have their needs met by learning disability services and that adults with AS who do suffer from mental health problems should have their needs met by local and specialist mental health services.

Unfortunately research carried out by the National Autistic Society suggests that in general individuals with AS are not getting the support they need from health and social services (Broach, S., Camgoz, S., Heather, C., Owen, G., Potter, D., Prior, A. 2003). They claim that because the needs and impairments of people with autistic spectrum disorders have only recently been acknowledged:

- Individuals often fall outside the eligibility criteria for existing support and services.

- Appropriate services are often not available.

- Professionals often lack training and/or experience.

Professionals in a London based Community Mental Health Team (CMHT) were interested to find out how well they were meeting the needs of clients with AS. In an effort to answer this question they commissioned the following research project. The objectives of this project were as follows:
• To identify the presenting needs of clients with a diagnosis of AS or suspected AS who have come into contact with five London based CMHTs since June 2002\textsuperscript{1}.
• To follow these clients' treatment paths.
• To ascertain whether these clients' needs have been met.
• To interview the CMHT Psychiatrists about their views on this issue.

2 Method

2.1 Design
This project involves an audit of 15 client files and 4 brief structured interviews.

2.2 Setting
Data was collected in five urban CMHTs who would typically provide services for adults with moderate to severe mental health problems living in the community, from a variety of social and economic backgrounds.

2.3 Participants
Participants included:
• 15 clients who came into contact with one of five London based CMHTs since June 2002. Two clients had a diagnosis of AS at first contact with the CMHT and 13 had suspected AS where this was clearly stated by a professional in the notes. They included 13 males and 2 females between the ages of 18 and 59.
• 5 Consultant Psychiatrists of which two were female and three male. One of the male Psychiatrists was excluded because he was new to the local and national service and felt unable to answer the interview questions.

\textsuperscript{1} Clients with suspected AS were included in the project because diagnosis is a common need identified by the NAS.
2.4 Procedures
A letter was sent to the managers of seven local CMHTs (see Appendix 1). The letter included a brief description of the project, a request to audit the files of clients who have come into contact with their CMHT since June 2002 with diagnosed or suspected AS and a request to interview the team Psychiatrist. Two managers were unable to participate.

The remaining five managers were then asked to put together a list of clients who have come into contact with their CMHT since June 2002 with diagnosed or suspected AS, where this is clearly stated by a professional in the notes. They were advised to base this list on their team’s memory for these clients since this appeared to be the only way of identifying the relevant clients.

2.5 Measures and schedules
The participants’ files were audited using an audit tool, which allowed all diagnoses, presenting problems and service outcomes to be recorded. The audit tool was developed on the basis of information gathered from a selection of client files. A space was then provided in each section of the audit tool for items that had not been identified during the pilot (see Appendix 2).

A presenting problem with activities of daily living (ADLs) was recorded when this was clearly stated by a professional in the notes or when the notes indicated that the client had difficulties with self care, home management and/or finance management. A presenting problem with social skills was recorded when this was clearly stated by a professional in the notes or when the notes indicated that the client had difficulties communicating with others and/or developing or maintaining relationships. A presenting problem with challenging behaviour was recorded when this was clearly stated by a professional in the notes or when the notes indicated that the client had difficulties with aggressive, violent and/or criminal behaviour. All other presenting problems were recorded when they were clearly stated by a professional in the notes.
An outcome of general CMHT care was defined as regular contact with a Community Social Worker, Psychiatric Nurse or Psychiatrist. All other outcomes were recorded when they were clearly stated by a professional in the notes. The appropriateness of outcomes for each presenting problem was not based on published standards since none were found. It was thus based on the capacity of each outcome to address the presenting problem and common practice in a CMHT setting.

The Psychiatrists for each team were interviewed using a structured interview schedule. The questions referred to specialist service provision for adults with AS within the trust, CMHTs ability to cater for their needs and Adult Mental Health Psychiatrists understanding of their needs and ability to make a diagnosis (see Appendix 3).

3 Results

3.1 Client Data

3.1.1 Diagnoses

Ten diagnoses were identified. Table 1 presents these diagnoses and their frequency in the sample studied.

Table 1: Frequency of Diagnoses among sample group

<table>
<thead>
<tr>
<th>Diagnoses</th>
<th>Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>8 (53%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>Psychosis/Schizophrenia</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>Physical Conditions</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Asperger Syndrome</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Mild Learning Disabilities</td>
<td>1 (7%)</td>
</tr>
</tbody>
</table>
The data presented in Table 1 suggests that the clients included in the study had more than one diagnosis each. The mean number of diagnoses per client was 1.8 (s.d = 0.9). See figure 1 for the distribution of diagnoses across the sample. The three most common diagnoses were depression, anxiety and psychosis/schizophrenia. The diagnosis of mild learning disability for one of the clients in the sample is surprising given its apparent incompatibility with a diagnosis of AS.
Figure 1: Distribution of diagnoses across sample

3.1.2 Presenting Problems

Nine presenting problems were identified. Table 2 presents these presenting problems and their frequencies in the sample studied.
Table 2: Frequency of presenting problems in the sample group

<table>
<thead>
<tr>
<th>Presenting Problems</th>
<th>Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Illness</td>
<td>14 (93%)</td>
</tr>
<tr>
<td>Social Skills</td>
<td>13 (87%)</td>
</tr>
<tr>
<td>Activities of Daily Living</td>
<td>10 (67%)</td>
</tr>
<tr>
<td>Cognition</td>
<td>8 (53%)</td>
</tr>
<tr>
<td>Employment</td>
<td>7 (47%)</td>
</tr>
<tr>
<td>Challenging Behaviour</td>
<td>6 (40%)</td>
</tr>
<tr>
<td>Physical Condition</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Request for Diagnosis</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Housing</td>
<td>2 (13%)</td>
</tr>
</tbody>
</table>

The data presented in Table 2 suggests that the clients included in the study had more than one presenting problem each. The mean number of presenting problems was 4.4 (s.d= 0.95). See figure 2 for a distribution of presenting problems across the sample. The most common presenting problem was mental illness. Eight clients had one diagnosis of mental illness and six had two diagnoses of mental illness. The second most common presenting problem was difficulties with social skills, which is characteristic of this client group. The high number of clients with difficulties finding employment may be another expression of the group’s difficulty with social interaction. The high number of clients reported to have cognitive impairments is surprising given the fact that people with AS are described as relatively high functioning.
3.1.3 Outcomes

Fourteen outcomes were identified. Table 3 presents these outcomes and their frequencies in the sample studied.

Table 3: Frequency of outcomes in the sample group

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral for Diagnosis</td>
<td>9 (60%)</td>
</tr>
<tr>
<td>CMHT Psychological Support</td>
<td>6 (40%)</td>
</tr>
</tbody>
</table>
The data presented in Table 3 suggests that the clients included in the study were offered more than one service each. The mean number of services offered was 3.2 per client (s.d. = 1.24). See figure 3 for the distribution of outcomes across the sample. The most frequently offered service was an assessment for diagnosis. Given that two clients had requested this service, it seems referrals were made for seven clients on the basis of professional suspicions. The second most frequently offered service was psychological support. This may be due to the high rate of mental illness in this sample. Interestingly, three out of thirteen clients with suspected AS were not offered an assessment for

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>General CMHT Support</td>
<td>6 (40%)</td>
</tr>
<tr>
<td>Referral to Day Center</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>Referral to Behavioural Unit</td>
<td>4 (27%)</td>
</tr>
<tr>
<td>Referral to Acute Inpatient Service</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Referral for Physical Activities</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Referral to Learning Disabilities</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>CMHT support with housing</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Referral for Residential Care</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Referral for Physical Care</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>CMHT support with employment</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Referral for Neuropsychological Assessment</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Referral to Rehabilitation Service</td>
<td>1 (7%)</td>
</tr>
</tbody>
</table>
diagnosis and eight out of fourteen clients with a mental illness were not offered psychological support. Furthermore the client who was diagnosed with mild learning disabilities was not referred to Learning Disability services and the three clients who were referred to Learning Disability services were turned down including the client who was not diagnosed with a mental illness.

![Distribution of outcomes across sample](image)

Figure 3: Distribution of outcomes across sample

Outcomes were then examined in relation to presenting problems. Table 4 presents appropriate outcomes for each presenting problem and their frequency.
Table 4: Appropriate outcomes for each presenting problem and frequency of cases with presenting problem where an appropriate outcome occurred

<table>
<thead>
<tr>
<th>Presenting Problems</th>
<th>Relevant Outcomes</th>
<th>Frequencies</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Request for Diagnosis</td>
<td>Referral for Diagnosis</td>
<td>2/2</td>
<td>100%</td>
</tr>
<tr>
<td>Housing</td>
<td>CMHT support with housing, Referral for Residential Care.</td>
<td>2/2</td>
<td>100%</td>
</tr>
<tr>
<td>Mental Illness</td>
<td>General CMHT Support, CMHT Psychological Support, Referral to Acute Inpatient Service, Referral for Residential Care.</td>
<td>12/14</td>
<td>86%</td>
</tr>
<tr>
<td>Activities of Daily Living</td>
<td>General CMHT Support, Referral to Day Center, Referral to Rehabilitation facility.</td>
<td>7/10</td>
<td>70%</td>
</tr>
<tr>
<td>Social Skills</td>
<td>General CMHT Support, Referral to Day Center, CMHT Psychological Support, Referral for Physical Activities</td>
<td>9/13</td>
<td>69%</td>
</tr>
<tr>
<td>Presenting Problems</td>
<td>Relevant Outcomes</td>
<td>Frequencies</td>
<td>Percentages</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------------------------------------------------</td>
<td>-------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Challenging Behaviour</td>
<td>Referral to Behavioural Unit, CMHT Psychological Support.</td>
<td>3/6</td>
<td>50%</td>
</tr>
<tr>
<td>Physical Condition</td>
<td>Referral for Physical Care</td>
<td>1/3</td>
<td>33%</td>
</tr>
<tr>
<td>Employment</td>
<td>CMHT support with employment</td>
<td>1/7</td>
<td>14%</td>
</tr>
<tr>
<td>Cognition</td>
<td>Referral for Neuropsychological Assessment</td>
<td>1/8</td>
<td>12%</td>
</tr>
</tbody>
</table>

The data presented in Table 4 suggests that on average, appropriate outcomes occurred for 59.4% of presenting problems (s.d = 31.9%). The mean number of appropriate outcomes for each client was 2.3 (s.d. = 1.25). See figure 4 for a chart representing the proportion of appropriately addressed problems for each client. Referral to a learning disability has not been listed as an appropriate outcome because it was not considered appropriate for any one of the presenting problems listed.
Figure 4: Number of met and unmet needs per client

3.2 Interview Data

Four consultant psychiatrists were interviewed using a structured interview schedule (see Appendix 3). The overall nature of their responses is presented in Table 5.
Table 5: Overall Nature of Consultant Psychiatrist responses to interview questions

<table>
<thead>
<tr>
<th>Questions</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you aware of any services that cater for the needs of people with AS</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>within the trust?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think CMHTs are able to cater for the needs of people with AS?</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Would you feel confident diagnosing AS?</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Do you feel confident in your understanding/knowledge of the condition?</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

The data presented in table 5 suggests that overall the interviewed psychiatrists had negative views about service and professional capacity to support people with AS. The two positive responses were given by the same individual and reflect a confidence in their own abilities. The data suggests that in this individuals’ opinion their confidence does not compensate for the incapacity of CMHTs to support people with AS.

In response to question 2, one psychiatrist stated that CMHTs are unable to cater for the needs presented by “a lot of less common conditions” and another that CMHTs’ ability to cater for the needs of people with AS “depends on what their needs are” and another “Learning Disability services have better experience and knowledge to deal with this
client group”. These comments suggest that service ability to cater for certain conditions may be related to the amount of exposure that service gets to them.

In response to question 3, one psychiatrist stated that their lack of confidence in diagnosing AS is related to the fact that they “don’t have enough exposure”. This comment reinforces the importance of exposure, which was suggested by the comments made in relation to question 2.

In response to question 4 one psychiatrist stated that they “need some training” to overcome their lack of understanding/knowledge of AS, suggesting perhaps that their professional or trust based training did not provide enough about this condition.

4 Discussion

The results of the file audit suggest that the clients in our sample had a high number of diagnosable conditions. The most common conditions were affective disorders, which supports Wing’s findings (1981). The results also suggest that the clients in our sample had a high number of presenting problems. The most common was mental illness, which suggests that the referrals being made to the CMHTs included in the study are in line with government guidelines. Overall the problems identified were similar to those reported by the NAS (Powell, 2001) and similar to those found in a typical CMHT client group. Another suggestion was that the clients in our sample were offered a high number of services. Although this implies some effort on the part of the CMHTs to address their needs there was also evidence of inconsistency in the teams’ approach to addressing those needs. The client who was not mentally ill was referred to Learning Disability (LD) services but turned down. It is likely that they did not fit LD eligibility criteria, which often stipulate that clients must have an IQ of less than 70. This is evidence for the confusion that exists over which service should take responsibility for this client group and for the NAS finding that these individuals often fall outside eligibility criteria for services (Broach et al., 2003). The analysis of outcomes in relation to presenting needs suggest that just over half of the needs presented were appropriately addressed. This
supports the idea that the CMHTs were not consistent in their approach to addressing needs and suggests that the services they offered were not always appropriate.

The results of the structured interviews suggest that although the CMHT's have access to specialist services for adults with AS, none of them are part of the relevant trust. This means that the referral process is more complicated and that a large area relies on few services. This supports the findings of the NAS (Broach et al., 2003). The results of the interviews also suggest that lack of exposure and training affects CMHTs' and AMH psychiatrists' ability to cater for the needs of this client group, which further supports the findings of the NAS (Broach et al., 2003). It seems surprising however that CMHTs should lack training and experience of catering for the needs of clients with AS given the apparent similarity between their needs and those of a typical CMHT client group. It is perhaps the combination of needs in each individual or the way those needs are presented that differentiates this group from a typical CMHT client group. If this is the case then our results seem to suggest that CMHTs require further training to improve their ability to cater for needs of this client group and at least some members with specialist experience.

There are also a number of reasons to question this study's findings. These include sample size and quality of sampling method, the definition of an appropriate outcome and the definition of a need that has been met.

The sample size reduces the conclusiveness of our results because it increases the risk of sampling bias. Although it is possible that very few clients with AS or suspected AS come into contact with CMHTs it is also possible that staff have a biased memory for these clients and consequently that our sample was unusual. It may therefore be advisable for the CMHTs involved in the study to keep a separate record of their caseload based on diagnosis or suspected diagnosis if they are planning to further investigate their performance with this or any other client group.
The definition of an appropriate outcome used in this study is vague. It is based on the researchers' clinical knowledge of the outcomes most suitable for each identified problem and of common practice in a CMHT setting. This does not necessarily determine their appropriateness. Outcomes are identified on an individual basis in CMHTs but insufficient information has been gathered to assess appropriateness on an individual basis. CMHT performance with regard to this client group may be better assessed with a case-by-case analysis of outcome appropriateness.

The definition of a met need in this study is also questionable since a referral to a particular service does not mean that a need will be met. This study does not include complete information on referral acceptance by services or clients or on needs being met as a result of referrals. As such appropriate outcomes, however we define them, do not necessarily indicate met needs. The assessment of met needs may be better achieved with a survey of client satisfaction.

In conclusion therefore it seems at first that the CMHTs included in the study are addressing the needs of clients with AS or suspected AS in inconsistent and sometimes inappropriate ways. However this may simply be a reflection of the poorly defined variables used in this study and recommendations have been made for future attempts to assess CMHT performance in this area. On the other hand the fact that team members report that a lack of experience and training with regards to this client group affects their ability and confidence to cater for their needs cannot be ignored.
References


Appendix I: Letter to CMHTs
Dear Mr XXX XXX,

I am a Trainee Clinical Psychologist on placement with the XXXX CMHT at XXXX Hospital in XXXXX. As part of my course work I have to carry out a Service Related Research Project and XXX XXX suggested you might be able to help.

I am interested in following the path of adults with Asperger’s who come into contact with Community Mental Health Services. I would like to review the services that are available to them.

For the purpose of this study I was wondering if it would be possible for me to look at the files of individuals who have been referred to you with diagnosed or suspected AS since June 2002. I was also wondering if it would be possible to talk to the Consultant Psychiatrist for your team about their views on this issue.

I plan to call in a couple of weeks time to discuss this further with you but if you would like to contact me sooner I am at the above address or telephone number on Wednesdays, Thursdays and Fridays.

Yours sincerely,
Trainee Clinical Psychologist
Appendix II: File Audit Questionnaire
A. Case Characteristics

• CMHT: .................................................................
• Client no: ..........................................................
• Male/Female: ................................................
• Age (yrs): ....................................................

Diagnosis:
- Asperger’s Syndrome
- None
- Psychosis/Schizophrenia
- Depression
- Anxiety
- Physical Illness

Other(s): ................................................................

B. Presenting Problems/Issues

• Activities of Daily Living
• Social Skills
• Challenging Behaviour
• Housing
• Employment
• Cognition
• Request for diagnosis
• Physical Health
• Mental Health

Other(s): ................................................................

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C. Outcomes

- CMHT services
  i. General
  ii. Psychology
  iii. Day Centre
  iv. Housing
  v. Employment
  vi. Inpatient
  vii. Physical Activities

- Referral
  i. For diagnosis
  ii. For neuropsychological assessment
  iii. For residential care
  iv. For treatment
    1. Learning Disabilities
    2. Behavioural Unit

Other: ........................................................................................................
........................................................................................................
........................................................................................................
Appendix III: Interview Schedule
Interview Schedule

1. Are you aware of any services that cater for the needs of people with Asperger's syndrome within the trust?

2. Do you think CMHTs are able to cater for the needs of people with Asperger's?

3. Would you feel confident diagnosing Asperger's syndrome?

4. Do you feel confident in your understanding/knowledge of the condition?
Feedback

The results of this research project are going to be presented to one of the CMHTs on the 14th of June 2004. The other CMHTs will be sent a copy of this report.

Proof of feedback

Dictated: 27th July 2004
Typed: 27th July 2004

Private & Confidential
PsychD Clinical Psychology
Dept of Psychology
University of Surrey
Guildford,
Surrey GU2 7XH

To Whom It May Concern:

I write to confirm that Emilie Cassel returned, as arranged, to Putney CMHT on 26th July 2004 and presented the results of her excellent small-scale research project to the MDT.

I understand this completes the requirements of her placement with us and that this letter will be attached to the record of her placement.

Please don't hesitate to contact me if you need further information.

Yours sincerely,

[Signature]
Major Research Project

Parents' views about the social well-being of their child with learning disabilities

May 2007
Year 3
Abstract

Parents' views about the social well-being of their child with learning disabilities.

Aim
To investigate the amount of support parents give their adolescent children with learning disabilities to make and maintain friendships and whether their perceptions of their child's social well-being, the importance of social well-being, the severity of their child's learning disability, the impact of individual characteristics on their child's social life and the impact of circumstances on their ability to care for their child had an effect on this.

Method
Seventy-three parents of children with learning disabilities between 11 and 19 completed questionnaires that included measures of the variables described above.

Results
The amount of support parents gave their children to make and maintain friendships were significantly positively correlated with their perceptions of the amount of recreational activities their children carried out with friends, significantly negatively correlated with their perceptions of the social impact of some of their children's characteristics and significantly positively correlated with their perceptions of the impact of some of their circumstances on their ability to care for their child.

Conclusions
Many of the young people with learning disabilities had few relationships and interactions with friends and many of their parents struggled to support them with this. This research suggests that it is important to take into account the complexities and reciprocities of the parent-child relationship when trying to understand this.
Acknowledgements

I would like to thank the schools that agreed to support the project by allowing me to contact their pupils' parents. I am particularly grateful to all the head teachers and school administration staff who helped with the distribution of research packs and to all the parents who returned completed questionnaires and flyers. I would also like to thank my supervisors Sue Thorpe, Nan Holmes and Elaine Creith for their assistance with the development of the questionnaire, analysis of the results and project write-up. I am particularly indebted to Sue Thorpe who supported me through some of the toughest times.

Finally I would like to thank my friends and family for their patience and support throughout the research project. I would especially like to thank them for always believing in me.
**Introduction**

This study sought to investigate whether parents' perceptions of their learning disabled child's social needs and abilities impact on their parenting strategies and whether certain other factors such as their beliefs about the importance of social wellbeing are associated with them being more or less responsive to their child's social needs and abilities. This line of enquiry was based on the current understanding that there are reciprocal influences between parents and their children and that parents of children with learning disabilities adjust their approach to parenting in response to their children’s specific needs and abilities. Social well-being, defined here as the experience of having relationships and participating in social and recreational experiences with friends, was chosen as the focus of this investigation because it appears to be an important factor in adolescents’ quality of life, mental and physical health, social and emotional development and academic achievement. It is also something that young people with learning disabilities often struggle to attain because of a range of factors including their own individual characteristics, their parents' attitudes and behaviours and society’s attitudes towards them. The research evidence for each of these statements will be discussed in turn, followed by a more detailed account of the aims of this study.

**The role of parenting in children’s development**

Understanding the role parents play in children’s development has attracted research attention for over half a century (Sears *et al.*, 1957). However, to date, no definitive or consensual theory of parenting has emerged. Instead research has moved towards theories about the relationship between specific aspects of parents’ behaviour or social cognitions and particular child outcomes. One of the most established theories is about the relationship between parental sensitivity and children’s social development (O’Connor, 2002).

The concept of parental sensitivity was first introduced by Ainsworth and her colleagues (1978) who found that parents’ responsiveness to their infants’ cries for attention determined the degree to which their child used them as a secure base from which to explore the world. She used this measure of the quality of mother-infant relationships to define secure and insecure attachment styles, which have since consistently been associated with aspects of children’s social and emotional
development. For example, in a review of findings from a comprehensive longitudinal study of care giving experiences, Sroufe (2002) reported that attachment style was particularly predictive of independence, social competence and emotional health. Of particular interest here is the relationship between attachment styles and children’s social relationships. Pre-school children with a history of secure attachment were more likely to exhibit appropriate emotions (concern) and social behaviour (e.g. calling a teacher) in the presence of an injured or distressed playmate than children with a history of insecure attachment (Kesterbaum et al., 1989). They were also more engaged with peers and more positive in their interactions with peers (Sroufe et al., 1984). In middle childhood, they developed more long-lasting friendships, took part more actively in same-sex peer groups, maintained better boundaries with respect to the opposite sex and coordinated friendship and group functioning more smoothly (Sroufe et al., 1999). In adolescence, they participated more successfully in mixed-gender peer groups (Englund et al., 2000) and were more able to tolerate intimacy, a characteristic that also defined their romantic relationships in adulthood (Brendgen, 2002).

In light of this and other evidence like this, developmental psychologists have felt justified in concluding that at least some aspects of parenting influence children’s development. However socialisation studies in general have received a great deal of criticism, leading some theorists to question whether parenting is that important at all. It has been suggested that this field of research suffers from theoretical, methodological and statistical weaknesses and that genetic effects can account for many of the reported findings (Harris, 1995, 1998).

In a damning critique of the nurture assumption, Harris accused developmental psychologists of oversubscribing to the belief that “parents are the most important part of the child’s environment and can determine, to a large extent, how the child turns out” (p15). She suggested that this caused some researchers to ignore other factors such as genetic influences. As an example of this she cited studies that look for evidence of parental influence between parents and their biological children where environmental and genetic effects are confounded (Scarr, 1993). Harris also proposed that being predisposed towards the nurture assumption led researchers to choose methodologies that did not allow the direction of influence between parents and
children to be detected. She highlighted the fact that correlational designs are often used in this field and that they are sometimes used to infer causality (Baumrind & Black, 1967).

Harris (1995, 1998) then argued that socialisation studies exaggerate the effects of parenting through their choice of methodologies and statistics. She criticised them for using the same informants to provide information about parental behaviour and child outcomes. Evidence that these kinds of within-informant correlations can be misleading was provided by Pike and colleagues (1996). They asked parents and adolescents to report on parents’ negative behaviour towards the adolescent and on the adolescents’ anti-social behaviour. Strong relationships were found between parents’ reports on their negative behaviour and adolescents’ anti-social behaviour and between adolescents’ reports on parents’ negative behaviour and their anti-social behaviour. However much weaker relationships were found between parents’ and adolescents’ reports of parents’ negative behaviours and between parents’ and adolescents’ reports of adolescents’ anti-social behaviours. Harris also suggested that socialisation studies find significant correlations by conducting too many analyses on too many variables, an approach that is widely believed to increase the risk of making type 1 errors (where the null hypothesis is rejected although it is actually true). Ultimately, Harris proposed that these studies under-report non-significant effects and over-report significant effects that are too small to be meaningful.

Harris (1995, 1998) then continued her argument against the importance of parenting effects by examining findings from behavioural-genetic studies. In this field, siblings with different levels of genetic similarity are compared in order to assess what proportion of the variance between them results from genetic, shared environmental and non-shared environmental influences. Shared environmental influences are conceptualised as those that result in similarities between siblings whereas non-shared environmental influences conceptualised as those that result in differences between siblings. Results of behavioural-genetic studies tend to indicate that 40-50% of the variance is attributable to genes (Plomin et al., 1994), 40-50% is attributable to non-shared environments and that just 0-10% is attributable to shared environments (Bouchard, 1994). Parenting clearly contributes to shared environmental influences. However it could also contribute to non-shared environmental influences if the
different ways in which parents rear their children are not solely influenced by their children's genetic makeup (in other words if gene-environment correlations are not solely attributable to genetic influence) or if children receive parenting in different ways (in other words if there are interactions between genetic and environmental factors). Harris reasoned that any differences in the ways in which parents rear their children must be driven by children's genetic makeup and found no evidence for children with certain genetic dispositions being more or less receptive to certain types of parenting. As such, she maintained that all aspects of parental influence belong to the category of shared environmental influences and thus have very limited effects on children's long-term development.

Perhaps not surprisingly, her thesis attracted a lot of return criticism. Generally, developmental psychologists have accused Harris of basing her arguments on research that took place before the early 1980's (Collins et al., 2000; Vandell, 2000). They agree that early researchers relied excessively on a deterministic view of parental influence and that early socialisation studies suffered from many methodological weaknesses that resulted in parental influences being overstated and other influences overlooked. However, they also direct Harris to more current parenting research and theory that addresses a lot of the issues she described. Contemporary socialisation theory no longer focuses on the main effects of parenting but attempts to describe the complex interaction between individuals and their environments. In this sense, it is no longer biased in favour of parenting but it has also moved beyond the traditional "additive" model of development that regards hereditary and environmental influences as independent, separable and together responsible for 100% of variance (Plomin, 1990).

In line with these theoretical developments and in response to criticism, modern socialisation researchers have made efforts to address the methodological and statistical flaws of earlier studies. As such they use longitudinal and experimental designs in which genetic and contextual factors are controlled for to try to detect parenting effects (Forgatch & Degarmo 1999; O'Connor et al., 1998; Srooife, 2002). In addition they use composite scores to reduce numbers of variables and multivariate analyses with adjusted alpha levels to reduce numbers of analyses (Vandell, 2000). Although the size of reported effects has not changed, Harris (1995) has been accused
of being overly critical in her judgment that they are too small to be meaningful (Rosenthal, 1994; Vandell, 2000). Critics have highlighted the fact that much smaller effect sizes are considered meaningful in clinical trials (Rosenthal, 1994) and that the size of reported effects reflect the complex developmental system that parenting is part of (Vandell, 2000). These new approaches to the study of socialisation have provided evidence that parent-child correlations reflect reciprocal influences between parents and their children (O’Connor et al., 1998). This suggests that parenting can be included in the category of non-shared environmental influences and that parenting accounts for more than just 0-10% of variance between siblings.

Consequently developmental psychologists have been able to demonstrate the importance of parenting by abandoning their bias towards parenting and thinking beyond the old “additive” model. In reality however, the idea of a reciprocal relationship between parents and children is not new. It was introduced in 1968 by Richard Bell who published a seminal article in which he criticised socialisation studies for solely focusing on the effects that parents have on children. He reviewed various lines of research that provided evidence that children also influence parents. This included research on families with children with disabilities. Some models of parental reactions to having a child with a disability that resulted from this research are examined in the next section.

The reciprocal relationship between parents and their disabled children
As Bell (1968) noted, the reciprocal relationship between parents and their disabled children has been studied for some time. Studies in this field suggest that parents become distressed when their child is diagnosed and can subsequently experience ongoing adaptation difficulties that affect the way they raise their child (Farber, 1959, 1960a, 1960b; Solnit & Stark, 1961). Parents’ experiences have been described and explained in different ways depending on researchers’ schools of thought. Fergusson (2002) found that researchers have tended to describe the nature of parental reactions in attitudinal terms such as panic or in operational terms such as self-blame. He also found that they described the source of these reactions as inherent to the impact of the disability on the family, for instance as part of a grief reaction, or as contextually determined by a variety of influences internal and external to the family, for example as a result of friends’ reactions.
According to this conceptual matrix, psychodynamic approaches primarily use attitudinal categories to describe parents' reactions to having a child with a disability and suggest that their reactions are an intrinsic part of the disability's effect on the family. For example, Solnit and Stark (1961) proposed that parents who have a child with learning disabilities experience a sense of loss when their child is diagnosed, the loss of the 'perfect' child they hoped for but never had. In response to this loss, they suggested that parents go through a mourning process. A later version of this model, put forward by Bicknell (1983), included the following stages in this mourning process: "shock, panic, denial, grief, guilt, anger, bargaining, acceptance, ego-centred work and other-centred work"1 (p 171).

Bicknell (1983) hypothesized that parents work through these stages at different rates and may work through them again at different points of their disabled child's life cycle. The continuing presence of the disabled child acts as a reminder of the absence of the perfect child and everything associated with it. These reminders are strongest at times when, due to cultural or family expectations, it is anticipated that the child should be reaching certain developmental milestones or at life transition phases. The mourning process is not always worked through completely and what was meant to be a transitional stage becomes a stage of fixation. This then leads to a maladaptive response. For example, when parents become stuck at the grief stage, they may become overprotective by not allowing their child to take risks or learn everyday life skills and by making them under-function. They may also become ambivalent by overprotecting and rejecting their child at the same time ("I love him but he is killing me", p 170). When parents become stuck at the anger or guilt stage they may become isolative and isolate themselves and their child from others.

Another approach to understanding parental reactions to having a child with a learning disability is the functionalist approach proposed by Murray and Cornell (1981). They viewed parental reactions as inherent to the impact of the disability on the family but described them with more operational terms. They suggested that parents experience a loss in response to their child's diagnosis: "a loss of [their]

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1 Definitions are included in Appendix I
opportunity to live vicariously through the accomplishments of their children” (p 202). In this model parents then experience a sequence of ‘mind sets’ that include: “Failure to believe, self-blame, anger and self pity and giving and sharing” (p 202). Those who fail to effectively work through these mindsets develop parentalplegia. This is a stress induced psycho-physiological condition caused by parents’ inability to adapt to their child’s disability. It can be recognised by extreme behaviours towards the child with a learning disability that become more severe as the child moves through life stages and that actually increase the child’s level of disability. Typical forms of parentalplegia described by the authors include overprotection (as described above), rejection where parents refuse to accept the disability and unrealistic prodding where parents continually push their child to do things they are not capable of.

In support of these models, other researchers have found evidence that parents of children with disabilities experience stages of adaptation like those described above (McKeith, 1973; Molsa & Ikonen-Molsa, 1985; Wetter, 1972) as well as increased distress at children’s life transition phases like when their child should be starting to walk, talk, ride a bicycle, drive a car or leave home (Roll-Pettersson, 2001; Wikler et al., 1981). In addition, some parents of children with disabilities have been reported to experience anxiety and depression that are known to have a negative effect on parenting (Crnic et al., 1983). In all between 20 and 50% have been found to fail to adapt to having a child with a disability and to have difficulties in their parenting (Barnett et al., 1999; Holder, 2004; Molsa & Ikonen-Molsa, 1985).

On the other hand these models have been criticised for taking an overly pathological and simplistic view of the effects of having a disabled child. They refer to ‘neurotic’ or ‘damaged’ families without allowing for the possibility that aspects of the mourning-adaptation process might be normal and helpful. For example, research has indicated that denial can sometimes constitute an adaptive coping strategy (McCollum & Gibson, 1970). In addition, they assume that all parents will react in similar ways. In fact, studies indicate that parents who have a history of difficult relationships are more vulnerable to adaptation difficulties (see Howe, 2006 for a review) and that parents who have support from spouses, family and friends are less vulnerable (Crnic et al., 1983). Finally, these models describe disability as a homogenous concept that
provokes the same reaction in all parents. To some extent this is understandable in the context of their frameworks. If parents are expecting a 'perfect child' or the experience of parenting a 'perfect child' then giving birth to anything other than a 'perfect child' is likely to be distressing. In reality, however, children with different disabilities present with different strengths and weaknesses, behavioural patterns and rates of development, which provoke different responses from parents (Dykens & Hodapp, 2001). For example parents of children with autism or behavioural problems experience more stress, depression and anxiety than parents of children with other presentations (Barnett et al., 1999; Donovan, 1988; Floyd & Gallagher, 1997).

Although 20-50% of parents struggle to come to terms with their child’s disability, it is now accepted that other parents adapt fairly well (Behr et al., 1992; Bennett et al., 1996; Summers et al., 1989). As a result, researchers have started to explore the ways in which these children’s different presentations influence parenting in non-pathological ways. For example, in a longitudinal study, Gallimore and colleagues (1989, 1999) found that parents’ expectations about the future functioning of their child with a learning disability correlated with their child’s current functioning. A path analysis revealed that the influence was transactional with parental expectations influencing children’s daily living competence and children’s daily living competence predicting future parental expectations. Similarly in two other longitudinal studies Nihira and colleagues (1983, 1985) examined the home environment and development of ‘trainable’ and ‘slow-learning mentally retarded’ adolescents. Their results indicated that the level of cognitive development of ‘trainable mentally retarded’ adolescents predicted the availability of cognitive stimulation in the home. In contrast, for ‘slow-learning mentally retarded’ adolescents it was their socio-emotional adjustment rather than their level of cognitive development that predicted families’ provision of educationally relevant stimuli and opportunities. In both cases, home environments then had a direct impact on adolescents’ development. These studies suggest that parents adapt their child rearing strategies to account for their perceptions of their child’s strengths and weaknesses and that these adaptations fulfil children’s needs. Following on from these findings, the present study sought to explore whether parents of adolescent children with learning disabilities adapt their child rearing strategies to account for their perceptions of their child’s strengths and weaknesses in social well-being (SWB).
However, the present study also took into account findings from research that demonstrates the concurrent impact of parents' beliefs on parenting choices. For example, studies have examined the influence of parents' beliefs or attitudes about the importance of their child having certain skills on their parenting approach. As such, Musun-Miller and Blevins-Knabe (1998) found that parents' beliefs about the importance of teaching children mathematics were positively correlated with parents' self reports of carrying out mathematic related activities with their child. In addition, Mize and colleagues (1995) found that parents' beliefs about the importance of peer relations were positively correlated with the number of play experiences they arranged for their children. In accordance with these findings, the current study aimed to explore parents' beliefs about the importance of SWB and how they impact on parenting strategies. SWB was viewed as a crucial part of adolescents' lives since research indicates that it promotes quality of life, physical and mental health and young people's academic, social and functional development. This evidence is reviewed in the next section.

The importance of social well-being

In the field of 'quality of life', conditions that are thought to be important for life satisfaction are often grouped together as core quality of life dimensions. For example relationships and interactions with friends tend to be included in the same dimension as relationships with family and/or community involvement (Schalock, 1996). SWB is thought to promote quality of life because the dimension that includes SWB has been identified as one of the most important domains of quality of life by samples drawn from the general population across the world (Abrahms, 1973; Cummins, 1996; Flanngan, 1978; Krupinski, 1980). SWB has also been identified as one of the most important dimensions of quality of life by people with learning disabilities (PWLD\(^2\)) and their carers. PWLD of all ages describe having friends as central to their overall satisfaction with life (Knox & Hickson, 2001; Janney & Snell, 2000). In addition parents and the professionals that work with PWLD spontaneously name SWB as a basic dimension of quality of life for PWLD (McIntyre et al., 2004; Petry et al.,

\(^2\) A definition of learning disability is included in Appendix II
Research demonstrates that there is good correlation between the views of PWLD and their carers in this area (Rapley et al., 1998).

Research on physical health suggests that SWB may also reduce the risk of illness (Cohen et al., 1997; Collins et al., 1993), enhance the rate of recovery from illness (Holahan et al., 1997; King et al., 1993; Wallston et al., 1983) and reduce the risk of mortality (House et al., 1988; Orth-Gomer & Johnson, 1987). Factors associated with SWB that have been identified as predictors of physical health include the support gained from social networks (Cohen et al., 2000) and the quality and quantity of social interactions (Kiecolt-Glaser & Newton, 2001). Then again, many of these studies do not preclude the role of other factors such as personality characteristics. For example, optimism is associated with increased social support (Brissette et al., 2002) and has also been shown to promote physical health (Helgeson, 1999; Helgeson & Fritz, 1999). Research on the relationship between SWB and physical health in PWLDs is hard to find.

Studies of mental health indicate that SWB may equally reduce the intensity of negative emotions and strengthens cognitive coping mechanisms (Cohen & Wills, 1985; Wrightsman, 1960). For example, studies of individuals that have experienced trauma have found that social support mediates the experience of psychological distress (Fleming et al., 1982; Haines et al., 1996; Sorkin et al., 2002). Bovier et al. (2004) found that this was because support gained from social relations is associated with strengthened internal resources and/or reduced amounts of perceived stress. This may be why population studies have repeatedly shown that people who are unmarried and socially isolated exhibit higher rates of psychiatric disorders (Brugha et al., 2005; Faris, 1934; Kohn & Clausen, 1955). PWLD who have positive relationships have similarly been shown to have lower levels of mental health problems (Wall, 1998) and higher levels of self-esteem (Smith & McCarthy, 1996) which is known to promote mental health (Mann et al., 2004). On the other hand these studies may simply show that people who are prone to psychological problems struggle to develop sources of social support or to benefit from them because they do not perceive them as such.
Moreover, SWB is thought to be a crucial part of development in adolescence. Young people of this age undergo puberty, start to develop a more sophisticated understanding of themselves and others and acquire greater independence. They also often reject the authority of their parents and align themselves with peers in an effort to define their own identities. Douvan and Adelson (1966) argued that these peer relationships are more intimate than at any other time in life and help foster self-esteem by allowing adolescents to feel respected for their ideas. Mannarino (1978, 1979) found evidence to support this idea in a study where adolescents with a stable and close best friend reported higher levels of self-esteem than those without. It was unclear however, whether differences between participants' levels of self-esteem were a consequence or a cause of their friendship styles. Douvan and Adelson (1966) also hypothesised that intimate relationships between adolescents contribute to the development of the social skills and sense of security that are important for intimate relationships in later life. In accordance with this, Maas (1968) found that adults with poor levels of intimacy had a history of poor intimacy in adolescence. As before however, a lack of tolerance for intimacy may have been a cause for their friendship patterns rather than a consequence. Finally, Douvan and Adelson (1966) proposed that intimate peer relationships help improve adjustment during adolescence by providing forums in which young people can share fears and anxieties about puberty. There is evidence that supportive peer relationships contribute to emotional and behavioural adjustment in adolescents but it is not clear whether this is specifically around issues related to puberty (DuBois et al., 2002).

Furthermore, research indicates that peer relationships can have a positive impact on adolescents' academic achievement. Adolescents' peer relationships are similar to other childhood relationships in that they are characterised by similarity in age, sex and race (Hallinan, 1979). Adolescent friends also have a similar orientation to school and to contemporary teen culture although this can develop during the course of the friendship (Kandel, 1978a, 1978b). Research shows that adolescents' educational aspirations and achievements can be altered as a result of peer pressure (Kandel, 1978a). This suggests that those who make friends with peers who perform better at school can be influenced to try harder and in some circumstances perform better.
themselves. However this also implies that young people who make friends that perform less well can be influenced to work less and achieve less.

Research on the role of SWB in the development of adolescents with learning disabilities has produced results that mirror those found in the general population. Adolescents with learning disabilities who have friends without learning disabilities tend to develop better academic, social and functional skills than those who do not (Fisher & Meyer, 2002; Hunt & Goets, 1997). In addition, adolescents with learning disabilities who have friends with learning disabilities can develop better social and behavioural skills but this depends on the type of friends they make (Farmer et al., 1993). Overall young PWLD who have social relationships when they leave school, tend to have good SWB later in life (Halpern, 1993). This suggests that the SWB of young PWLD in secondary school may be an important indicator for their current and future quality of life.

The importance of SWB for young PWLD is now so widely accepted that the UK government has made promoting SWB a major goal for services that work with PWLD. This is made clear in the government’s white paper Valuing People: A new strategy for learning disability for the 21st century (2001) where a number of relevant objectives are laid out. These include:

- “[ensuring] that disabled children get maximum life chance benefits ... while living with their families...” (Objective 1: Children and young people, p122);
- “increasing the number of disabled children who use inclusive play, leisure and cultural services including holiday play schemes, after school clubs and preschool clubs...” (Sub-objective 1.6, p123);
- “[enabling] people with learning disability to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships.” (Objective 7: Fulfilling lives, p127).

It is also made clear in the government’s National Service Framework for children, young people and maternity services (2004). This document sets out several relevant standards of care and service delivery such as:
• "The health and well-being of all children and young people is promoted and delivered (...) to ensure long term gain..." (Standard 1: Promoting health and well-being, identifying needs and intervening early, p6);

• "Parents or carers are enabled to receive the information, services and support which will help them to care for their children and equip them with the skills they need to ensure that their children have optimum life chances and are healthy and safe." (Standard 2: Supporting parenting, p6);

• "Children and young people who are disabled or who have complex health needs receive (...) child and family-centred services which (...) promote social inclusion and, where possible, which enable them and their families to live ordinary lives." (Standard 8: Disabled children and young people and those with complex health needs, p7).

In summary, research evidence provides some indication that social relationships and interactions mediate satisfaction with life, health, academic performance and social and functional development in adolescents in the general population and PWLD. This has resulted in SWB being made a focus for services that work with young PWLD in the UK. Despite this, studies continue to indicate that some young PWLD struggle to make and maintain friendships. Research on the actual SWB of young PWLD is reviewed below.

**Actual social well-being of young people with learning disabilities**

Studies that examine the social relationships and interactions of young PWLD often use educational settings as the context in which to base their investigations. Young PWLD in developed countries can be educated in integrated schools (IS) that cater for pupils with and without learning disabilities or in special needs schools (SNS) or vocational academies that tend to cater solely for pupils with learning disabilities. Unfortunately research indicates that they struggle to achieve SWB in all three kinds of educational establishment (Heiman, 2000; Smith & Sykes, 1981; Williams & Asher, 1992).
Secondary school students with learning disabilities that attend IS appear to be less liked, more frequently rejected and more frequently ignored than their non-disabled peers (Cooney et al., 2006; Guralnick & Groom, 1987; Guralnick et al., 1996b; Sabornie & Kaufman, 1987; Williams & Asher, 1992). Moreover, they tend to have a low social status, few friends and remain socially isolated (Faught et al., 1983; Guralnick & Groom, 1988; Guralnick et al., 1996a; Taylor et al., 1987). They are also less satisfied with their friendships (Brantley et al., 2002), feel less included (Watson & Keith, 2002) and are lonelier (Heiman & Margalit, 1998) than students without disabilities. Some studies have failed to detect social status difficulties amongst learning disabled students in IS (e.g. Sabornie & Kauffman, 1986) but none have found students with learning disabilities to have a higher social status than their non-disabled peers. In a review of studies on this topic Dudley-Marling & Edmiaston (1985) concluded that students with learning disabilities were more likely to have low social status than their non-disabled peers.

Secondary school students with learning disabilities who attend SNS can also struggle to achieve SWB (Heiman, 2000; Heiman & Margalit, 1998). Although they may not suffer the same amount of rejection from peers, studies show that some students continue to feel isolated and often fail to build friendships that they can enjoy outside of the school environment. Heiman (2000) found that preadolescent and adolescent students with learning disabilities who attended SNS had even fewer friends and reported feeling lonelier than students with learning disabilities at IS. They also only saw their friends at school. Studies that have examined these children’s social relationships and interactions outside of educational settings support these findings. Smith and Sykes (1981) conducted interviews with parents of 21 adolescents attending a centre preparing them for independence and employment. They found that 44% had either no friends or just one or two and spent most of their leisure time alone. Orsmond and colleagues (2004) interviewed and gave questionnaires to 235 mothers about their adolescent child with autism. Almost half (46.4%) of their sample had no friends. In this last example, the number of peer relationships was predicted by certain child characteristics such as age and level of social skills impairment. Participation in recreational activities was predicted by certain parental factors such as maternal participation as well as certain child characteristics.
As such it seems that young PWLD in SNS, IS and vocational academies can have difficulty achieving SWB even though it is widely recognised as an important part of their development, well-being and health. Research suggests that there are many barriers to SWB in this population including some child characteristics, parental attitudes (Orsmond et al., 2004; Lehmann & Baker, 1995) and social attitudes (Siminski, 2003). A brief description of these factors and the ways in which they can act as barriers to SWB is given below. This provides some background for the investigation into the relationship between parents’ perception of some of these factors and their parenting strategies carried out in the current study.

**Barriers to social well-being**

Child characteristics that have been associated with poor SWB include those that are found in all PWLD such as impaired intellectual and social/adaptive functioning and some that are not found in all PWLD but that are relatively common such as challenging behaviours, sensory difficulties, mobility problems and communication difficulties (Emerson et al., 2001; Enderby & Davies, 1989; McLaren & Bryson, 1987; Office of Population Censuses and Surveys, 1988; Qureshi & Alborz, 1992). Research indicates that the SWB of young PWLD is likely to be affected by these characteristics because:

- Impaired intellectual and social/adaptive functioning\(^7\) have been shown to cause young PWLD to mature at a slower rate than their non-disabled peers and make them less able to process social information and ascertain the most appropriate behaviour in social situations (Baron-Cohen, 1985; Beadle-Brown et al., 2002, 2005; Bryan, 1974; Bryan & Pflaum, 1978; Geisthardt & Munsch, 1996; Heiman, 2000; Kronick, 1978; Nowicki, 2003; Orsmond et al., 2004; Wiig & Harris, 1974).

- Challenging behaviours\(^8\) have been found to increase the chances of young PWLD being excluded from services (Emerson et al., 1987) and rejected by their peers (Felce et al., 2000; Kistener & Gatlin, 1989).

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\(^6\) A more detailed description of research on barriers to SWB is included in appendix III

\(^7\) See appendix II for definitions of impaired intellectual and social/adaptive functioning; These factors were examined in the current study in terms of severity of disability

\(^8\) See appendix II for definition of challenging behaviour
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- Sensory difficulties\(^9\) have been shown to impede social interactions with people who have intact senses and linked with difficulties building social relationships, loneliness, rejection and social isolation (Foster, 1988; Huurre & Aro, 1998; Kef, 1997; MacCuspie, 1992; Mertens, 1989; Stinson et al., 1996;) in non-learning disabled individuals.
- Motor impairments have been associated with anxiety in non-learning disabled adolescents (Sigurdson et al., 2002) and exclusion from services that promote SWB in young PWLD\(^{10}\).
- Communication difficulties have been linked with poor social competence (Beadle-Brown et al., 2002; McCabe & Meller, 2004) and challenging behaviour, which are known to have negative impact on social relationships (Hummel & Prizant, 1993).

Parental factors that have been related to poor SWB include parents’ lack of efforts to support the development of their child’s SWB, parents’ beliefs about their child’s vulnerability and their willingness to allow their child to plan their own leisure time (Lehmann & Baker, 1995; Smith & Sykes, 1981; Zetlin & Murtaugh’s, 1988). Evidence suggests that parents of PWLD play a major role in orchestrating their social lives (Krauss et al., 1992; Seltzer & Krauss, 1999; Seltzer et al., 2002). This implies that they are partly responsible for the SWB of their children. However, research shows that in some cases parents do not provide the support required for their children to develop friendships. Smith and Sykes (1981) found that parents were aware that their children had few friends, even spoke with regret about their children’s lack of friends and hobbies, but did not make efforts to tackle these issues. In another study 60% of mothers admitted that their children’s best friends were immediate or extended family. Although they wanted them to have other friends, they all expressed a fear of their children being taken advantage of (Lehmann & Baker, 1995). In addition, research shows that some young PWLD are not given the freedom to plan social activities for themselves. Over half of Zetlin and Murtaugh’s (1988) sample

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\(^9\) See appendix II for definitions of sensory difficulties

\(^{10}\) Current UK legislation instructs services to provide additional support for young people with mobility problems who are technology dependent (Valuing People, 2001). However services do not get extra funding to finance this. Informal discussions with parents of young PWLD indicate that technology dependent children are sometimes excluded from after school clubs because these services cannot afford to provide the extra staff required.
spent weekends and holidays alone or with family who acted as chaperones rather than as friends. They found that this was because their parents did not let them plan their own spare time. Similarly, in Orsmond and colleagues’ (2004) study, adolescents with autism were more likely to take part in social and recreational activities when their mothers took part in similar activities.

Parental factors that have not been explicitly associated with poor SWB but are hypothesised to be related to it in the present study include parental income, caring responsibilities, working hours and external support. Parents may not be able to afford promoting SWB in their child with learning disabilities. They may have additional caring responsibilities that make them less available to support the development of their child’s social network. They may also be less available if they care for other children or adults with disabilities or illness, have mental or physical health problems of their own or work unusual hours. However, in these cases the SWB of young PWLD may be protected by the presence of external support. Evidence suggests that mothers with learning disabled adolescent children rely heavily on formal support from professional bodies (Donovan, 1988) and on informal support from family and friends (White & Hastings, 2004).

Social attitudes towards people with disabilities that have been linked to poor SWB in young PWLD are those that result in discrimination. The Union of the Physically Impaired Against Segregation in 1976 (as cited in Siminski, 2003) described the experience of being discriminated against in their social model of disability. In this model ‘impairment’ is distinguished from ‘disability’ in the following sense:

- Impairment is “the functional limitation within the individual caused by physical, mental or sensory impairment” and
- Disability is “the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers” (Disabled People’s International as cited in Siminski, 2003).

This model proposes that people with disabilities are not prevented from leading ‘normal’ lives by their own characteristics or impairments but by a society that does not take their needs into account and does not therefore offer them equal opportunities. Providing young PWLD with equal opportunities to develop SWB
might involve supporting them to access social events by ensuring they have suitable information, transport and facilities like ramps and toilets.

Consequently research suggests that certain child characteristics can act as barriers to SWB in young PWLD by affecting their ability to interact and build relationships with others. In addition parental factors can prevent the development of SWB in this population by causing parents not to provide young PWLD with the support they need to achieve it. Furthermore social attitudes can hinder the achievement of SWB in young PWLD through discrimination.

Conclusion
The research described above suggests that parents adapt their parenting strategies in response to their children’s particular strengths and weaknesses as well as their beliefs about what skills are important for their children to develop. It also indicates that young PWLD struggle to attain SWB in a range of educational settings despite the fact that it is believed to be important for their quality of life, health and development. Barriers to SWB in this population can include young people’s own characteristics, their parents’ attitudes and behaviours and societal attitudes. In view of this evidence, the current study sought to investigate whether parents change their approach to parenting in accordance with their beliefs about the importance of SWB, their perception of their learning disabled adolescents’ level of SWB and their perception of factors that impact on their children’s ability to achieve SWB or on their ability to care for their children.

A survey method was used to investigate parents’ views about the SWB of their adolescent child with learning disabilities. This included an exploration of their perception of the level of their child’s SWB, the severity of their child’s disability, the aspects of their child’s presentation that they feel impact on their child’s SWB, the aspects of their own circumstances that they feel interferes with their ability to care for their child, their views about the importance of SWB and their child’s access to and use of resources to make and maintain friendships as a measure of their supportive behaviour. This approach, used in many studies of parents’ views about having a child with a disability (Pelchat et al., 1999; Skotko & Canal-Bedia, 2005; White & Hastings, 2004), was chosen because it meant a large number of parents
could be contacted in an effort to obtain a large and representative sample. It also allowed for a lot of very specific information to be obtained without interviewer bias and for hypotheses to be tested using robust statistical analyses. Another advantage of using this method included potentially obtaining more accurate information since participants could take the time to reflect on their responses in a less anxiety provoking and intrusive context than an interview. Disadvantages of using this method included not being able to get in depth information about people’s experiences, limiting the involvement of parents with learning disabilities of their own and getting socially desirable responses. However, efforts were made to overcome some of these issues. These shall be described in the method section.

Aim and research questions

• Aim

To investigate the amount of support parents give their adolescent children with learning disabilities to make and maintain friendships and whether their perceptions of their child’s SWB, the importance of SWB, the severity of their child’s learning disability, the impact of individual characteristics on their child’s social life and the impact of circumstances on their ability to care for their child have an effect on this. This will be explored by looking at particular research questions.

• Research questions

1. Are parents’ perceptions of their child’s level of SWB related to the amount of support they give their child to make and maintain relationships?

2. Are parents’ beliefs about the importance of SWB related to the amount of support they give their child to make and maintain relationships?

3. Are reports of the severity of young people’s disabilities related to the amount of support parents give their child to make and maintain relationships?
4. Are parents’ perceptions of the impact of child characteristics on their child’s SWB related to the amount of support they give their child to make and maintain relationships?

5. Are parents’ perceptions of the impact of their own circumstances on their ability to care for their child related to the amount of support they give their child to make and maintain relationships?

6. Which of the factors examined in previous research questions best predict the amount of support parents give their child to make and maintain relationships?

7. How do the factors examined in previous research questions interact with each other in their relationship with the amount of support parents give their children to make and maintain friendships?
Method

Participants
Parents of young PWLD aged between 11 and 19 were invited to participate in this study. Recruitment lasted 5 months. Parents were recruited from five SNS and one IS across three London boroughs. SNS and IS offer an alternative curriculum for young people who are unable to follow the mainstream curriculum. SNS cater specifically for pupils who have learning disabilities whereas IS cater for both pupils with and without learning disabilities. Of 686 parents contacted, 73 returned completed questionnaires (a response rate of 10.6%).

A power analysis calculated using G*Power software (Erdfelder et al., 1996) indicated that for a medium effect size, with $\eta^2 = 0.3$, a total sample of 64 participants was required with alpha = 0.05 and a power of 80%. The number of parents that participated in the study exceeded this figure.

Participants comprised of 73 adults (59 females, 8 males and 6 who did not disclose their gender). Their mean ages were 41.3 years for females (Standard deviation, SD = 5.5) and 48.4 years for males (SD = 10). Sixty-eight were biological parents, 3 were foster carers, 1 was an adoptive parent and 1 had an “other” type of relationship to the young PWLD who were the focus of the questionnaire. Information about the parents’ highest level of education is provided in appendix IV. Information about socio-economic status and ethnic background was not gained directly from parents. However figures from the Office of National Statistics (ONS) give some indication of these factors in the local population. This information is provided in appendix V.

Design
The project was a correlational design. Individuals’ ratings in different domains were examined and compared.

Measures
A questionnaire\textsuperscript{11} was developed with the help of an expert in the field of psychological research and survey/questionnaire design and an expert in the field of

\textsuperscript{11} See appendix VI
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learning disabilities. Both had at least ten years work experience. This added to the questionnaire’s content validity. Likert scales were favoured because they ensured the collection of specific information and because they were considered easier to complete for participants with time restrictions and/or limited literacy. This questionnaire is described in full below.

- **Questions 1-4:** Demographic details of parents’ gender, age, highest level of education and relationship to the young PWLD in question.

- **Question 5:** Parents’ views about the impact of a series of parental circumstances on their ability to care for their child with learning disabilities.
  - **Scale structure**
    Participants were asked to select one of six responses (doesn’t apply/not at all/very little/somewhat/quite a lot/very much) for each of 7 items. Items related to parental income, working hours, caring for other children, caring for adults, parental physical health and emotional issues.
  - **Scoring methodology**
    Each response was associated with a number between 0 and 5. This resulted in a range of scores between 0 and 5 for each item and between 0 and 35 for the scale total.
  - **Scale development**
    The scale was developed according to the suggestion, put forward in this study, that parents with children with learning disabilities may be less able to support their children to develop and maintain SWB when they have certain life circumstances.\(^\text{12}\)

- **Questions 6-9 and 11:** Demographic details of young PWLD’s age, gender, access to support and possession of a statement of educational need (SEN).\(^\text{13}\)

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\(^{12}\) See introduction for more details

\(^{13}\) A statement of educational need is allocated to children and young people who have special needs for support to obtain an education. It is allocated following an in depth assessment by Children’s Services which is reviewed on a regular basis.
• **Questions 10 and 12**: Parents’ views about the severity of their child’s disability and their reports of the severity of disability described in young people’s SEN.
  
  o **Scale structure**
  
  Parents were asked to choose from five possible responses (very mild/mild/moderate/severe/very severe) to describe both their views and the views expressed in young people’s SEN.
  
  o **Scoring methodology**
  
  Responses were given a score between 0 and 5.
  
  o **Scale development**
  
  These scales were developed on the basis of research that relates SWB to severity of disability (Heiman, 2000).

• **Question 13**: Parents’ views about the impact of a series of child characteristics on young people’s social life.
  
  o **Scale structure**
  
  Participants were asked to select one of five responses (see question 5) for each of 14 items. Items described challenging behaviours, sensory difficulties, communication difficulties and mobility problems.
  
  o **Scoring methodology**
  
  Each response was associated with a number between 0 and 5, so that scores ranged between 0 to 5 for each item and 0 to 120 for all child characteristics.
  
  o **Scale development**
  
  The scale was developed on the basis of research reviewed in the introduction that indicates that these factors could impact on the social adjustment of PWLD (Kistener & Gatlin, 1989; Stinson *et al.*, 1996; MacCuspie, 1992; Beadle-Brown *et al.*, 2002; Sigurdson *et al.*, 2002).

• **Question 14**: Parents’ views about the importance of a series of factors for their child’s current and future well-being.
  
  o **Scale Structure**
  
  Participants were asked to select one of six responses (doesn’t apply/of no importance/of little importance/important/very important/extremely important) for
Each of 30 items. These items were indicators for Schalock’s (1996) eight domains of quality of life. These domains were:

- **Emotional well-being** e.g. safety, spirituality and happiness
- **Interpersonal relations** e.g. affection, intimacy and friends
- **Material well-being** e.g. employment, possessions and money
- **Personal development** e.g. education, skills and purposeful activity
- **Physical well-being** e.g. health, nutrition and recreation
- **Self-determination** e.g. autonomy, choice and personal goals
- **Social inclusion** e.g. acceptance, status and residential living
- **Rights** e.g. privacy, access and citizenship

Of the 30 items, 4 items were related to emotional well-being, 4 items were related to interpersonal relations, 4 items were related to material well-being, 4 items were related to personal development, 4 items were related to physical well-being, 3 items were related to self-determination, 4 items were related to social inclusion and 3 items were related to rights.

- **Scoring methodology**
  These responses were associated with numbers between 0 and 5 so that scores ranged between 0 and 5 for each item, 0 and 20 for domains with 4 items, 0 and 15 for domains with 3 items and 0 and 150 for all domain indicators.

- **Scale development**
  Cronbach’s alpha (1960) was calculated to measure the reliability of the overall scale and the social wellbeing scale. The alpha coefficient for the scale was 0.9, which suggests it has good internal reliability and 0.6 for the subscale, which suggests it has average internal reliability.

**Question 15**: Parents’ views about the frequency with which young people carried out a series of social and recreational activities.

- **Scale structure**
  Participants were asked to select from five responses (never/a few times a year/about once a month/a few times a week/about once a day) for each of 57 items. Of these 57 items, 15 described activities carried out alone, 16 described
activities carried out with family and 26 described activities carried out with friends.

- **Scoring methodology**
  Each of these responses was associated with a number between 0 and 5 so that scores ranged from 0 to 5 for each item, 0 to 75 for activities carried out alone, 0 to 80 for activities carried out with family, 0 to 130 for activities carried out with friends and 0 to 285 for all activities.

- **Scale development**
  This scale was inspired by a similar scale used by Orsmond *et al.*, (2004) in a study of peer relationships and recreational activities in adolescents and adults with autism. Items from this scale were amended on the basis of the researcher’s knowledge of children’s activities in the UK in 2006. Items relating to activities carried out with family and alone were included to obtain a measure of activity levels in other contexts.

- **Question 16:** Parents’ views about the availability, accessibility, aided and independent use of resources used to make and maintain social contacts.
  - **Scale structure**
    Participants were asked to choose one of four responses (resource not available/does not have access/uses with help/uses independently) for each of 7 items. The items referred to resources used to make and maintain social contacts such as a home telephone, mobile telephone, and emailing facilities.
  - **Scoring methodology**
    Each response was associated with a number between 0 and 3, with scores above 0 reflecting the availability of a resource, scores above 1 reflecting the accessibility of a resource, scores of 2 reflecting the use of a resource with help and scores of 3 reflecting the independent use of a resource.
  - **Scale development**
    The items were put together on the basis of the researcher’s knowledge of communication and travel technology that is commonly used to make and maintain social contacts by adolescents and adults in the general population.
• **Question 17:** Parents’ views about the frequency with which young people used the resources described above.

  o **Scale structure**
  
  Participants were asked to choose one of five possible responses (see question 15) for each of 8 items. The items described the action of using each of the resources described above.

  o **Scoring methodology**
  
  Each response was associated with a number between 0 and 5 so that scores ranged from 0 to 5 for each item and from 0 to 40 for all items.

• **Question 18:** Parents’ views about each person in their child’s social network in terms of their relationship to each other, how close they were to each other and how often they saw each other.

  o **Procedure**
  
  Participants were asked to place each person who was important to their child in one of three concentric circles. They were requested to place those to which their child felt closest in the inner circle, those to which their child felt not quite so close but who were still really important in the middle circle and those to which their child felt not so close again but who still quite important in the outer circle. This was based on the adult convoy structure mapping procedure developed by Antonucci (1986) and adapted for children by Levitt *et al.*, (1993). An added request of participants was that they indicate how the people they placed in the circles were related to their child and how often they saw their child.

  o **Scoring methodology**
  
  For the purpose of this study, people placed in the circles described as friends were counted and frequency of contact was given a score according to the scale used in question 15.

  o **Scale development**
  
  Levitt *et al.*, assessed the test-retest reliability of the measure. They found reliability coefficients of 0.9 for the total number of people in the social networks of children of all ages and 0.75 for children of 14 years of age. This suggests that the measure has good test-retest reliability.
• **Question 19-20:** Details of what parents' felt were other obstacles to young people's social life and ways in which services could improve their child's social network, opportunities and activities.
  
  o **Scale structure**
  
  These two last questions were open ended and intended to give participants an opportunity to make comments they had not had the opportunity to make elsewhere in the questionnaire as well as give their views on ways in which services could support them in this area. It was anticipated that they might provide some of the more in depth information about people’s experiences that is usually lacking in quantitative studies.

  o **Analysis methodology**

  Parents' answers were analysed using content analysis (Weber, 1990).

**Procedure**

• **Recruitment: phase 1**

The head teachers and director of two SNS and one IS in a London borough were contacted in writing to request a meeting to discuss their possible involvement in the study. They all attended meetings with the researcher to discuss the documentation, procedure and their involvement in the study.

Their proposed role involved providing a covering letter for the research packs indicating to parents that they had given permission for them to be contacted by researchers. They would then be expected to distribute the research packs to the parents of pupils between 11 and 19 years of age with learning disabilities attending their school/college. The researcher would prepare the packs and fund the distribution if the research packs could not be given to the pupils to take home. They all agreed to take on this role.\(^\text{14}\)

The director of the IS advised that the young people should be given the opportunity to consent to their parents sharing information about them. The consent form was therefore amended and a young person's information sheet was developed to provide young people with sufficient information to give informed consent.

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\(^{14}\) See appendix VII for covering letters
The head teachers and director warned the researcher that some parents would be unable to complete the questionnaire due to their own learning disabilities. They also indicated that there was a risk of a poor response rate since their pupils’ parents often failed to return forms. As a result, plans were put in place to support parents with difficulties and ensure an optimal response rate. It was decided that all parents would be given the researcher’s contact details and asked to contact her if they needed help completing the questionnaire. In addition, in one of the SNS the headmaster would offer support in person or over the phone. In the other SNS and the IS, support would be offered in drop-in sessions facilitated by the researcher. In both the SNS and the IS, a second distribution of research packs would take place in the event of a poor response rate.

- Development of research packs

The second stage of the procedure was the development of research packs containing the questionnaire, information sheet for parents, young people’s information sheet, consent form and local support services sheet.

Questionnaire

The questionnaire was developed as described above (see Measures). It was then piloted with five parents who were asked to comment on their experience of completing the questionnaire. These parents did not have children with learning disabilities because the principal researcher was not in contact with parents of children with learning disabilities at the time. While parents may not have known about the issues related to SWB for young PWLD they were likely to be aware of the factors related to SWB for young people in general. In addition they were able to comment on the experience of using the questionnaire to give specific information about their child’s behaviour, activities and social network. These factors and the limited time frame for the study suggested that asking these parents to participate in the pilot study was acceptable. Their feedback included comments about instructions given in the questionnaire, which were amended accordingly. Two parents suggested that the questionnaire was too long, however the breadth of information required for the study resulted in a decision being made to preserve the length of the questionnaire.
Information sheet

An information sheet was developed to provide parents with details about the study so they could make an informed decision about taking part\(^\text{15}\). This information included answers to questions like:

1. What is the research about?
2. Do I have to take part in the study?
3. Will my involvement in the study be kept confidential?
4. What will happen to the results of the study?

Young people's information sheet

An information sheet was developed for young people with details of the study so that they could make an informed decision about their parents taking part\(^\text{16}\). The details provided were the same as those provided for parents but described in simpler terms.

Consent form

A consent form was designed so that parents could indicate that they had made an informed decision to participate in the study\(^\text{17}\) and where possible gained permission from the young person who was the focus of the questionnaire. This included statements about taking part voluntarily, young people having read the information sheet and given permission and the possibility of withdrawing from the study at any time without giving a reason.

Local support services sheet

A local support services sheet was developed to provide parents with information about the resources available to them and their child with a learning disability in the area. It was hoped that this would be helpful to parents if they did have concerns as a result of completing the questionnaire\(^\text{18}\).

Ethics

The documentation and planned procedure described above was included in an application for ethical approval from the University of Surrey Research Ethics

\(^{15}\) See appendix VIII for parents' information sheet  
\(^{16}\) See appendix VIII for young people's information sheet  
\(^{17}\) See appendix IX for consent form  
\(^{18}\) See appendix X for local support services sheets
Committee. The confidentiality of information provided by parents and the anonymity of parents were assured. Ethical approval was granted\(^{19}\).

- **First distribution**

Two hundred and thirty research packs were prepared for the parents of each pupil at participating schools. They contained a covering letter written by the school/college head teacher/director, the information sheet for parents, the young person’s information sheet, the consent form, the questionnaire, the sheet with information about local support services and a stamped addressed envelope to the researcher at the University of Surrey. The packs were then delivered to the SNS and IS who distributed them to parents.

The parents of pupils who attended one of the SNS and the IS were offered a choice of two drop-in sessions held at each establishment by the researcher if they wanted help completing the questionnaire or if they had questions about the study. Sessions were held at different times of the day to increase accessibility. No parents attended these. One parent made contact with the researcher over the telephone to ask for clarification about one of the items. Another was supported to complete the questionnaire by his child’s head teacher.

- **Recruitment: Phase 2**

The response rate from the first distribution of research packs was very poor so efforts were made to recruit more participants.

Another 205 research packs were prepared including a handwritten letter from the researcher in place of the covering letter from the school/college head teacher/director\(^{20}\). These were then sent out by one of the SNS and the IS one to two months after the first distribution. Parents of pupils who attended the other SNS were contacted by telephone by the school administrator to encourage participation. This resulted in a further four research packs being sent out.

\(^{19}\) See appendix XI for ethics committee letter of approval

\(^{20}\) See appendix XII for handwritten note
Recruitment: Phase 3

The response rate from the second distribution was better than the first but still not sufficient. As a result, SNS from adjoining boroughs were approached to take part in the study. The head teachers of three SNS in two other London boroughs were contacted in writing to request a meeting to discuss their possible involvement in the study. Two head teachers agreed to participate over the telephone and sent a covering letter to the researcher. One head teacher agreed to participate and provided a covering letter during a meeting with the researcher. The covering letters were then submitted to the University Ethics Committee in order to obtain ethical approval to approach the parents of pupils at these schools. Approval was granted. In total 462 research packs were prepared as described above and delivered to the schools to be distributed. The response rate for this distribution was 7.8%.

Generalisability

The overall response rate (10.6%) was quite low compared to other survey studies and the majority of parents did not request support to complete the questionnaire. This suggested that participating parents were sufficiently able to complete the questionnaire without help and that the length and complexity of the questionnaire may have prevented less able parents from participating. This raised concerns about how representative the sample was of the wider community of parents of PWLD and therefore how generalisable the results were. Several ways of exploring these issues were considered including organising a focus group in which parents of mixed abilities could be asked about the possible characteristics of non-responders. This approach was not taken because of concerns about the representativeness of parents who might volunteer to participate in such a focus group.

Instead a flyer was developed that described the main results of the study and asked parents to indicate whether or not the results reflected their personal experience, how things were generally and if they had previously completed one of the study’s questionnaires. It was then presented to a group of 10 parents of mixed abilities at a voluntary organisation for children with learning disabilities and their carers based in

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21 See appendix XIII for phase 3 covering letters
22 See appendix XIV for second ethics committee letter of approval
23 See appendix XV for generalisability investigation flyer
the first London borough the study was conducted in. This was meant to test the accessibility of the flyer for people of mixed abilities and to obtain the views of parents with disabilities of their own. They all felt that the flyer was accessible and that the results reflected their own experience and how things are generally. None of them had previously completed one of the study’s questionnaires. Their other views are reported in the results section. The flyer was then submitted to the University Ethics Committee in order to obtain ethical approval for it to be distributed to all the parents that had previously been sent questionnaires. Approval was granted.

- **Analysis**

  - **Quantitative Data**
  
  SPSS version 12 was used to analyse the quantitative data. A number of composite variables were calculated using raw data from the questionnaire. These are described in the results section. Parametric analyses were used where possible.

  - **Qualitative Data**
  
  The qualitative data obtained from the open-ended questions 19 and 20 was examined for themes using content analysis. This is a way of reducing verbal material to a set of relevant and manageable categories (Silverman, 2001). The themes were chosen on the basis of the barriers to SWB explored in the introduction and issues raised through informal discussions with parents (Dunphy *et al.*, 1989). The reliability of the analysis was ensured by having parents’ responses re-analysed with the same categories by an independent rater. There was a 71.3% level of agreement between the independent analyses of responses related to further obstacles to young people’s social lives and an 83.6% level of agreement between those related to service development ideas. This suggests that the initial analysis of responses was moderately to highly reliable.

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24 See appendix XVI for third ethics committee letter of approval

25 See appendix XVII for results of the independent analysis
Results
The results are presented in five sections. The first includes a consideration of parametric assumptions. The second includes descriptive information about the young people who are the focus of this study and computed variables. The third includes analyses based on the study’s research questions. The fourth includes analyses of qualitative responses. The fifth includes details of the generalisability investigation.

Parametric assumptions

- Data levels
Parents' views were mostly obtained using likert scales. It has become common practice to treat data that has been obtained in this way as if it were interval level data, which can be subjected to parametric testing. An example of this approach can be found in the study conducted by Ormond et al., (2004) on the peer relationships and social and recreational activities of adolescents and adults with autism.

- Homogeneity of variance
Homogeneity of variance is a requirement for parametric analyses of data obtained from unrelated samples because it implies that samples are drawn from the same population. It is not a requirement for parametric analyses of data obtained from related samples because data sets are known to come from the same sample (Coolican, 1999).

- Distribution
Normal distributions were assessed with the One-Sample Kolmogorov-Smirnov test. Most variables were normally distributed. The following were not:
  o Choice of severity of disability descriptor by parents
  o Choice of severity descriptor in SEN
  o Friend network size
  o Friend network quality
  o Frequency of contacts with friends
  o Number of activities alone
  o Frequency of activities alone
  o Resource availability
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- Number of resources used independently
- Number of unaided resource activities

The results of distribution skewness and kurtosis assessments carried out on these variables are reported in appendix XVIII. Attempts to transform them into normal distributions were unsuccessful. They could therefore not be used in parametric analyses.

Descriptive information

- Young people

The ages of young people referred to in this study ranged from 11 to 19 and averaged at 14.3 years (standard deviation, SD = 1.9). Forty-eight (65.8%) were male and twenty-five (35.2%) were female. Seventy-one (97.3%) were said to have an SEN. One of the young people who did not have an SEN had recently left school (age 16). It is unclear why the other young person did not have an SEN since they were attending a SNS.

- Severity of disability

Parents' choice of term to describe the severity of their child's learning disability and their reports of the term used to describe the severity of their child's learning disability in the SEN are presented in table 1. Most parents (n = 37) and SEN (n = 32) described young people's learning disabilities as severe.

<table>
<thead>
<tr>
<th>Parent's choice of descriptor (n = 72)</th>
<th>Very Mild</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Very severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5</td>
<td>28</td>
<td>37</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Descriptor used in SEN (n = 66)</th>
<th>Very Mild</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Very severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>3</td>
<td>27</td>
<td>32</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

The relationship between parents' choice of descriptor and descriptor use in SENs was examined to see if there was agreement between parents and the education service on the best way to describe the severity of young people's disabilities. The
results of a spearman’s correlation indicate that there was a significant positive correlation ($r = 0.866$, $n = 65$, $p < 0.01$) between parents’ choice of descriptor and descriptor use in SENs. This suggests that there was a high level of agreement between parents and education services in terms of the best way to describe young people’s disabilities.

Information about the nature and severity of young people’s difficulties was also obtained directly from the IS and indirectly from Ofsted reports on four of the SNS\textsuperscript{26}. It was not available for one of the SNS because it closed in October 2006. Information about the nature of young people’s difficulties indicated that across five of the participating schools, the majority of pupils had general learning disabilities and a small minority had autistic spectrum disorders, emotional, social and behavioural disorders, speech and language disorders or sensory impairments. Information obtained about the severity of young people’s difficulties indicated that in four out of five schools the majority of pupils had moderate learning disabilities and a minority had severe learning difficulties. In the other the majority of pupils had severe learning disabilities. This suggests that parents of young people with severe learning disabilities were more highly represented in the sample of parents that participated in the current study than they were in most participating schools.

- **Young people’s social well-being**

There were five measures of young people’s SWB including ‘friend network size’, ‘friend network quality’, ‘frequency of contacts with friends’, ‘number of activities carried out with friends’ and ‘frequency of activities carried out with friends’.

  - **Friend network size**

The size of young people’s network of friends was calculated by counting the number of friends parents placed in each of three concentric circles. If parents referred to “friends” without specifying how many, it was assumed they meant two friends. On average young people were reported to have 2.9 friends ($SD = 3.4$; range: 0-13). The

\textsuperscript{26} This is included in appendix XIX along with information about the prevalence of specific disorders amongst children in the general population.
distribution of friend network sizes is presented in figure 1. A large number of parents (n = 21) did not place any friends in any of the three concentric circles suggesting that their child did not have any friends.

![Figure 1: Distribution of friend network sizes (total n = 73)](image)

Levitt et al., (1993) suggest that the social network mapping procedure used here, should detect expected differences in social network structure across age groups. They found evidence that non-disabled children included more friends in their social network at adolescence then at age 10. A one-tailed Spearman’s correlation was computed to investigate whether these expected differences could be detected in the current sample. This was not significant suggesting that friend network sizes did not increase with young people’s age in this sample.

In addition, Nowicki, (2003) and Orsmond et al. (2004) report that children with more severe learning disabilities tend to have fewer friends. A one-tailed Spearman’s correlation was computed to investigate whether children in the current sample with more severe learning disabilities also had fewer friends. There was a significant negative correlation (r = -0.3, n = 71, p<0.01) between parents’ reports of the severity
of their child's disability and the number of friends in their social network. This suggests that parents who perceived their child to be more severely disabled also perceived them to have fewer friends.

- **Friend network quality**

The social network mapping procedure provides a measure of close friend network size, moderately close network size and distant friend network size. These are obtained by counting the number of friends in the inner, middle and outer circles respectively. The mean close friend network size was less than 1 (SD = 0.4; range 0-2), whilst the mean moderately close friend network size was 1.6 (SD = 1.9; range 0-10) and the mean distant friend network size was 1.2 (SD = 2.2; range 0-11). This reflects the fact that a large proportion of parents placed no friends in the inner (n = 65), middle (n = 30) or outer circle (n = 44).

The use of three concentric circles to reflect friend closeness also allows for an analysis of friend network quality. In order to achieve this, a score was given to each parent on the basis of whether they placed the majority of their child's friends in the inner, middle or outer concentric circles. Parents with a score of 1 were said to have children with a friend network of poor quality because they had placed the majority of their child's friends in the outer circle (for distant friends). Parents with a score of 2 were said to have children with a friend network of moderately good quality because they had placed the majority of their child's friends in the middle circle (for moderately close friends). Parents with a score of 3 were said to have children with a friend network of good quality because they had placed the majority of their child's friends in the inner circle (for close friends). If participants placed the same number of friends in two or three of the circles, they were given the highest of the two or three scores available according to the circles in question. Twenty-three parents could not be given a score. Two of these had not responded to question 18 and twenty-one had not placed any friends in their child's social network. The distribution of parents across friend network quality types is presented in figure 2. Most parents (n = 34) reported that their child had a network of friends of moderate quality and more parents (n = 13) reported that their child had a network of friends of poor quality than of good quality (n = 3).
Figure 2: Distribution of friend network quality scores (total n = 50)
**Frequency of contacts with friends**

Parents were asked to indicate how often their child made contact with the people they placed in the three concentric circles. This was an addition to the original social network mapping procedures put forward by Antonucci (1986) and Levitt et al., (1993) meant to allow for an analysis of the frequency with which young people made contact with their friends. The contact frequencies reported by parents were assigned a value according to the five point scales used in questions 15 and 17. The highest value was recorded for each concentric circle to represent the highest frequency with which children were reported to have contact with close friends, moderately close friends and distant friends. Highest frequency values were then used to calculate the mean frequency with which parents reported that their child had contact with friends for analyses based on the study’s hypotheses. Mean frequencies ranged from 2.5 to 5 and averaged at 3.9 (SD = 0.7).

Mean frequencies were then grouped together to correspond to the original frequency categories for the purpose of description. In this case means of 2.5 were taken to represent ‘about once a month’ and means between 3 and 3.5 were taken to represent ‘a few times a month’, and means between 3.67 and 4.5 were taken to represent ‘a few times a week’ and means of 5 were taken to represent ‘about once a day’. The resulting distributions of mean frequencies of contacts with friends are presented in figure 3. Most of the parents who had reported that their child had friends (n = 23) reported that they saw their friends a few times a week.
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Figure 3: Distribution of frequencies of contacts with friends (total n = 43)

- Number of recreational activities carried out

The numbers of activities young people were reported to carried out with friends, family or alone were calculated by counting the number of activities parents reported their child carried out more often than ‘never’. The number of activities carried out with friends ranged from 1 to 17 and averaged at 7.26 (SD = 4.45). The number of activities carried out with family ranged from 1 to 14 and averaged at 8.58 (SD = 3.11) and the number of activities carried out alone ranged from 0 to 7 and averaged at less than one (SD = 1.22). The proportions of total numbers of recreational activities carried out with family, friends or alone are presented in figure 4. Most parents reported that their child carried out no activities alone and a large proportion reported that their child carried out more activities with family than with friends.
A related t-test was carried out to investigate whether young people were actually reported to carry out more activities with their friends or family. There was a significant difference ($t = -2.792$, $df = 72$, $p<0.01$) between the numbers of reported activities with friends and the numbers of reported activities with family members, suggesting that young people were reported to carry out significantly more activities with family than with friends.

**Frequency of recreational activities carried out**

The frequencies with which parents reported that their child carried out activities with each friend were used to calculate the mean frequency with which their child carried out activities with friends. These mean frequencies ranged from 0.04 to 1.42, averaged at 0.49 (SD = 0.32). Frequencies with which parents reported that their child carried out activities with family members and alone were manipulated in the same way for comparison purposes. The mean frequencies with which parents reported
their child carried out activities with family ranged from 0 to 2.75 and averaged at 0.91 (SD = 0.42) whereas the mean frequencies with which parents reported that their child carried out activities alone ranged from 0 to 0.8 and averaged at 0.09 (SD = 0.17). This is because most parents (n = 69) reported that their child ‘never’ carried out activities alone.

Mean frequencies were then grouped together according to the original frequency categories used in question 15 for description purposes. Means between 0 and 0.5 were taken to represent ‘never’, whilst means between 0.51 and 1.5 were taken to represent ‘a few times a year’, and means between 1.51 and 2.5 were taken to represent ‘about once a month’ and means of more than 2.51 were taken to represent ‘a few times a month’. The resulting distribution of mean frequencies for each type of activity is presented in table 2. Most parents reported that their child carried out activities with family a few times a year (n = 59) but never carried out activities alone (n = 69) or with friends (n = 43).

<table>
<thead>
<tr>
<th>Scale categories</th>
<th>N*</th>
<th>Never</th>
<th>A few times a year</th>
<th>About once a month</th>
<th>A few times a month</th>
<th>About once a week</th>
<th>About once a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities alone (15)</td>
<td>72</td>
<td>69</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Activities with friends (25)</td>
<td>72</td>
<td>43</td>
<td>29</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Activities with family (16)</td>
<td>72</td>
<td>10</td>
<td>59</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
*Data missing for one participant

A related t-test was carried out to investigate whether young people were reported to carry out activities more frequently with family or friends. Results indicated that there was a significant difference between the frequency of activities carried out with friends and the frequency of activities carried out with family members (t = -8.49, df = 71, p<0.001), suggesting that young people were reported to carry out activities with family significantly more frequently than with friends.
• **Resources used to make and maintain social contacts**

There were three measures of the support parents gave their children to make and maintain social contacts including ‘resource accessibility’\(^{27}\), ‘number of aided resource activities’\(^{28}\) and ‘frequency of aided resource activities’\(^{29}\). The ‘number of unaided resource activities’ and the ‘frequency of unaided resource activities’ were also examined and are reported for the purpose of comparison. ‘Resource availability’, ‘aided use’, ‘independent use’ were also examined but are not reported here\(^{30}\).

  o **Resource accessibility**

The total number of accessible resources was obtained by counting the number of resources listed in question 16 parents gave a score of 2 or 3. The distribution of numbers of accessible resources ranged from 0 to 7, averaged at 4.35 (SD = 1.94) and is presented in figure 5. This indicates that more than half of the young people referred to in the study (n = 38) were reported to have access to five or more resources to make and maintain social contacts. The accessibility of each resource across the sample is presented in appendix XX.

\(^{27}\) This refers to whether a young person has parental permission to use a resource
\(^{28}\) This refers to activities young people carry out with resources they require assistance to use
\(^{29}\) This refers to the frequency with which aided resource activities were carried out
\(^{30}\) See appendix XX for details of these measures
The number of aided resource activities young people were reported to carry out was obtained by counting the number of activities listed in question 17 parents reported they carried out more often than never (score 1 to 5) with resources they had reported they needed help to use in question 16. The distribution of total numbers of aided resource activities young people carried out ranged from 0 to 6, averaged at 1.93 (SD = 1.62) and is presented in figure 6. This shows that a large proportion of young people referred to in the study (n = 19) were reported not to carry out any aided resource activities.

See appendix XX for details of the aided use of resources
The number of unaided activities young people were reported to carry out was obtained by counting the number of activities listed in question 17 parents reported they carried out more often than ‘never’ (score 1 to 5) with resources they had reported they could use independently in question 16\textsuperscript{32}. The distribution of total numbers of unaided resource activities ranged from 0 to 7, averaged at 1.36 (SD = 1.88) and is presented in figure 7. This indicates that the majority (n = 38) of young people referred to in the study were reported not to carry out any unaided resource activities.

\textsuperscript{32} See appendix XX for details of the unaided use of resources
A Wilcoxon signed ranks test was carried out to investigate whether young people were reported to carry out more activities with resources they needed help to use than with resources they could use independently. No significant differences were found.

**Frequency of activities carried out with resources**

The frequencies with which young people were reported to carry out activities with resources were used to calculate the mean frequencies with which young people were reported to carry out aided and unaided resource activities. The mean frequencies with which young people were reported to carry out aided resource activities ranged from 0 to 5 and averaged at 1.61 (SD = 1.15). They were then grouped together according to the original frequency categories used in question 17 for the purpose of description. Means between 0 and 0.5 (n = 10) were taken to represent ‘never’; means between 0.6 and 1.5 (n = 23) were taken to represent ‘a few times a year’; means between 1.6 and 2.5 (n = 17) were taken to represent ‘about once a month’; means between 2.67 and 3.5 (n = 6) were taken to represent ‘a few times a month’; means between 4 and 4.5 (n
were taken to represent ‘a few times a week’ and means of 5 (n = 1) were taken to represent ‘about once a day’. The resulting distribution of mean frequencies of aided resource use is presented in figure 8. It shows that most young people (n = 23) were reported to only engage in aided resource activities a few times a year.

Figure 8: Frequency with which young people carry out aided resource activities (total n = 60)

The mean frequencies with which young people were reported to carry out unaided resource activities ranged from 0 to 5, averaged at 2.38 (SD = 1.69). They were then grouped together according to the original frequency categories used in question 17 for the purpose of description. Means of 0 (n = 9) were taken to represent ‘never’; means between 1 and 1.33 (n = 7) were taken to represent ‘a few times a year’; means between 1.67 and 2.5 (n = 5) were taken to represent ‘about once a month’; means between 2.57 and 3.5 (n = 10) were taken to represent ‘a few times a month’; means between 3.63 and 4.5 (n = 9) were taken to represent ‘a few times a week’ and means of 5 (n = 4) were taken to represent ‘about once a day’. The resulting distribution of mean frequencies of unaided resource use is presented in figure 9. It shows that
similar numbers of young people were reported to engage in unaided resource activities a few times a year (n = 7) and a few times a week (n = 9).

![Pie chart showing frequency of unaided resource activities]

**Figure 9: Frequency with which young people carry out unaided resource activities (total n = 44)**

A related t-test was carried out to investigate whether young people were reported to carry out activities more frequently with resources they need help to use or those they could use independently. No significant differences were found.

**• Parental attitudes towards quality of life domains**

Parents were asked to rate how important they felt a series of factors were for their child's current and future well-being. These factors were indicators for eight domains of quality of life (Schalock, 1996). The importance ratings parents gave to each indicator of SWB are presented in table 3 as an example.\(^{33}\)

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\(^{33}\) Importance ratings given to other indicators are presented in appendix XXI
The majority of parents rated most indicators as ‘extremely important’. This indicates that responses were negatively skewed and that a factor analysis would not produce meaningful results. This is because correlations based on distribution similarities would not reflect underlying constructs (Nunnaly & Bernstein, 1994). As a result a decision was made to investigate parents’ attitudes towards the SWB domain with which the scale was constructed (Schalock, 1996). Parents’ attitudes towards other domains are presented in appendix XX.

The mean of importance ratings given to each of the four indicators of SWB (see table 3) was calculated to represent the importance parents attributed to SWB for their child’s current and future well-being. Ratings of 0 were excluded from these calculations as they represented the response ‘doesn’t apply’. SWB importance scores ranged from 3 to 5, and averaged at 4.4 (SD = 5.1). They were then grouped together to correspond to the original response categories for description purposes. Importance scores between 3 and 3.5 (n = 7) were taken to represent the category ‘important’, those between 3.75 and 4.25 (n = 26) were taken to represent the category ‘very important’ and those between 4.5 and 5 (n = 39) were taken to represent the category ‘extremely important’. The resulting distribution of SWB importance scores is shown in figure 10. It shows that most parents (n = 39) rated SWB as being ‘extremely important’.

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**Table 3: Number of parents endorsing each indicator of SWB**

<table>
<thead>
<tr>
<th>Scale items</th>
<th>N*</th>
<th>Doesn’t apply Rating: 0</th>
<th>Of no importance Rating: 1</th>
<th>Of little importance Rating: 2</th>
<th>Important Rating: 3</th>
<th>Very important Rating: 4</th>
<th>Extremely important Rating: 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having close personal relationships</td>
<td>71</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>13</td>
<td>25</td>
<td>30</td>
</tr>
<tr>
<td>Having support from friends and family</td>
<td>72</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>21</td>
<td>49</td>
</tr>
<tr>
<td>Having friends</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>8</td>
<td>21</td>
<td>43</td>
</tr>
<tr>
<td>Having social interactions</td>
<td>72</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>10</td>
<td>27</td>
<td>32</td>
</tr>
</tbody>
</table>

*Data were missing for some participants.
• **The impact of child characteristics**

Parents were asked to indicate to what extent a series of characteristics interfered with their child’s social life. These impact ratings were then used to calculate mean impact ratings for each child characteristic. Mean impact ratings were 2.5 (SD = 1.5) for hearing difficulties, 2.1 (SD = 1.25) for incontinence, 2.7 (SD = 1.35) for property destruction, 2.4 (SD = 1.3) for mobility problems, 2.6 (SD = 1.33) for inappropriate personal habits, 2 (SD = 1.3) for self injury, 3.3 (SD = 1.4) for problems speaking, 1.9 (SD = 1.2) for visual difficulties, 2.5 (SD = 1.1) for physical aggression, 3.4 (SD = 1.2) for problems understanding, 2.8 (SD = 1.3) for making disturbing noises, 2.7 (SD = 1.3) for tantrums, 3.3 (SD = 1.3) for requiring constant attention and 2.5 (SD = 1.3) for antisocial behaviour. They are presented in figure 11.

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34 Distributions of child characteristics impact ratings are presented in appendix XXII
35 Impact ratings of 0 were excluded because they indicated that a characteristic ‘did not apply’.
Impact ratings were also used to calculate the mean overall impact of child characteristics on young people’s social lives. This was represented by the mean of impact ratings for all child characteristics. These mean impact scores ranged from 1.33 to 4.58 and averaged at 2.7 (SD = 0.86). Mean impact scores were then grouped together according to the original impact categories used in question 13 for the purpose of description. Means between 1.33 and 1.5 (n = 6) were taken to represent ‘Not at all’; means between 1.6 and 2.5 (n = 27) were taken to represent ‘very little’; means between 2.54 and 3.5 (n = 25) were taken to represent ‘somewhat’; means between 3.57 and 4.44 (n = 13) were taken to represent ‘quite a lot’ and means of 4.58 (n = 1) were taken to represent ‘very much’. The resulting distribution of means of all impact ratings is presented in figure 12. Most parents (n = 27) reported that their child’s characteristics had ‘very little’ impact on their social lives.
• Parent issues
  o Parental sources of support

Forty-two (57.5%) parents reported that they did not receive support from another adult or organisation whilst thirty (41.1%) reported that they did. Parents’ descriptions of the types of support they received were used to group them. The proportion of parents that received each type of support is presented in figure 13. ‘Other support’ included support from specific organisations such as The Autistic Trust and carer support groups. Most of the parents (n = 20) that reported receiving support, reported that they were supported by their family.
The impact of parental circumstances

Parents were asked to rate how much a series of parental circumstances impacted on their ability to care for their child with learning disabilities\(^{36}\). These impact ratings were then used to calculate mean impact ratings for each circumstance\(^{37}\). Mean impact ratings were 2.7 (SD = 1.35) for income, 3.3 (SD = 1.2) for working hours, 3.3 (SD = 1.3) for caring for other children, 3 (SD = 1.8) for caring for other disabled children, 2.6 (SD = 1.6) for caring for adults, 2.2 (SD = 1.3) for parents’ own emotional issues and 2.4 (SD = 1.3) for parents’ own physical issues. They are presented in figure 13.

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\(^{36}\) The distributions of parental circumstance impact ratings are presented in appendix XXIII

\(^{37}\) Ratings of 0 were excluded as they indicated that a circumstance ‘did not apply’.
Figure 13: Mean impact ratings for each parental circumstance

Impact ratings for parental circumstances were also used to calculate the mean impact of all parental circumstances. These overall mean impact scores ranged from 1 to 5 and averaged at 2.74 (SD = 0.9). They were then grouped together according to the original impact categories used in question 5 for the purpose of description. Means between 1 and 1.5 (n = 10) were taken to represent ‘Not at all’; those between 1.75 and 2.5 (n = 20) were taken to represent ‘very little’; those between 2.6 and 3.5 (n = 25) were taken to represent ‘somewhat’; those between 3.57 and 4.5 (n = 13) were taken to represent ‘quite a lot’ and those of 5 (n = 1) were taken to represent ‘very much’. The distribution of mean impact scores for all parental circumstances is presented in figure 14. Most parents (n = 25) reported that their circumstances had ‘somewhat’ of an impact on their ability to care for their child.
Analyses based on research questions

- Research question 1

*Are parents' perceptions of their child's level of SWB related to the support they give their child to use resources to make and maintain relationships?*38

One-tailed Pearson’s and Spearman’s correlations were computed to investigate the relationship between measures of parents’ perceptions of young people’s SWB and of the support they give young people to use resources to make and maintain relationships. Results indicated that parents’ perceptions of the number of activities young people carry out with friends were positively correlated with their reports of the number of aided resource activities young people carry out ($r = 0.22, n = 73$, $p<0.05$), the frequency with which young people carry out aided resource activities ($r$

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38 See appendix XXIV for results of all relevant analyses
Major Research Project

= 0.28, n = 60, p<0.05) and young people’s access to resources (r = 0.33, n = 73, p<0.01). Furthermore, parents’ perceptions of the frequency with which young people carry out activities with friends were positively correlated with their reports of the frequency with which young people carry out aided resource activities (r = 0.28, n = 60, p<0.05) and young people’s access to resources (r = 0.25, n = 72, p<0.05). These results suggest that young people who were perceived to carry out higher numbers of activities with friends were also reported to carry out higher numbers of aided resource activities, to carry out aided resource activities more frequently and have more access to resources. Furthermore, young people who were perceived to carry out activities with friends more frequently were also reported to carry out aided resource activities more frequently and to have more access to resources.

• Research question 2

*Are parents’ beliefs about the importance of SWB related to the support they give their child to use resources to make and maintain relationships?*

One-tailed Pearson’s and Spearman’s correlations were computed to investigate the relationship between measures of parents’ views about the importance of SWB and of the support they give their child to use resources to make and maintain relationships. No significant correlations were found.

• Research question 3

*Are parents’ perceptions of the severity of their child’s disability related to the amount of support they give their child to use resources to make and maintain relationships?*

One-tailed Spearman’s correlations were computed to investigate the relationship between measures of the severity of young people’s disabilities and of the support parents give their child to use resources to make and maintain relationships. No significant correlations were found.

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39 See appendix XXV for results of all relevant analyses
40 See appendix XXVI for results of all relevant analyses
• Research question 4

Are parents' perceptions of the impact of child characteristics on their child's SWB related to the amount of support they give their child to use resources to make and maintain relationships?41

One-tailed Pearson’s and Spearman’s correlations were computed to investigate the relationship between measures of parents’ perceptions of the overall impact of young people’s individual characteristics on their social lives and of the support they give their child to use resources to make and maintain relationships. No significant correlations were found.

One-tailed Pearson’s and Spearman’s correlations were then computed to investigate the relationship between measures of parents’ perceptions of the social impact of specific child characteristics and of the support they give their child to use resources to make and maintain relationships. Results showed that parents’ reports of the number of aided resource activities young people carry out were negatively correlated with their perceptions of the social impact of inappropriate personal habits (r = -0.23, n = 56, p<0.05) and self injury (r = -0.31, n = 43, p<0.05). In addition, parents’ reports of young people’s access to resources were negatively correlated with their perceptions of the social impact of property destruction (r = -0.27, n = 50, p<0.05), self-injury (r = -0.36, n = 43, p<0.01) and problems speaking (r = -0.25, n = 66, p<0.05).

These results suggest that young people who were reported to carry out fewer aided resource activities were perceived to be more socially impaired by inappropriate personal habits and self-injury. In addition, they imply that those who were reported to have less access to resources were perceived to be more socially impaired by a tendency to destroy property, self injury and problems speaking.

41 See appendix XXVII for results of all relevant analyses
• **Research question 5**

*Are parents' perceptions of the impact of their own circumstances on their ability to care for their child related to the amount of support they give their child to use resources to make and maintain relationships?*\(^{42}\)

One-tailed Pearson's and Spearman's correlations were computed between measures of parents' perceptions of the overall impact of their circumstances on their ability to care for their child and their reports of the support they give their child to use resources to make and maintain relationships. No significant correlations were found.

One-tailed Pearson's and Spearman's correlations were then computed to investigate the relationship between measures of parents' perceptions of the impact of specific parental circumstances and of the support they give their child to use resources to make and maintain relationships. Results indicated that parents' reports of the number of aided resource activities carried out by young people were positively correlated with their perceptions of the impact of caring for other disabled children \((r = 0.36, n = 26, p<0.05)\) and caring for adults \((r = 0.51, n = 20, p<0.05)\). They also showed that parents' reports of the frequency of aided resource use by young people were positively correlated with their perceptions of the impact of their own physical problems \((r = 0.26, n = 41, p<0.05)\).

These results suggest that parents who reported that caring for other disabled children and caring for other adults had a greater impact on their ability to care for the young person who was the focus of the study also reported that their child carried out more aided resource activities. They also indicate that parents who reported that their own physical problems had a greater impact on their ability to care for their child also reported that their child carried out resource activities more frequently.

In addition independent samples t-tests were computed to compare the amount of support given by parents who had external support with that given by parents who did not. No significant differences were found.

\(^{42}\) See appendix XXVIII for results of all relevant analyses
• **Research question 6**

*Which of the factors examined in previous research questions best predict the amount of support parents give their child to make and maintain relationships?*

The results of a stepwise multiple regression to establish which of three variables best predicted the number of reported aided resource activities young people carried out was considered unreliable. This is because two of the variables had too few cases for this type of analysis (Howitt & Cramer, 1997). The results of two other stepwise multiple regressions were considered unreliable because of the multicollinearity between measures of parents’ perceptions of their child’s SWB. Parents’ perceptions of the number and frequency of recreational activities their children carried out were highly positively correlated with each other ($r=0.86$, $p<0.01$, $n=72$). They were also equally related to the frequency of aided resource activities ($r=0.28$, $n=60$, $p<0.05$) and similarly related to resource accessibility (number of activities: $r=0.33$, $n=73$, $p<0.01$ and frequency of activities: $r=0.25$, $n=72$, $p<0.05$). This resulted in a high risk of one measure being identified as a better predictor because it has a minutely better correlation with the dependent variable than another measure. Given that these measures were obtained from responses to self-completion questionnaires, part of their variance may be due to the fact that they were obtained from the same source and not because they are more or less related to the dependent variable.

• **Research question 7**

How do the factors examined in previous research questions interact with each other in their relationship with the amount of support parents give their children to make and maintain friendships?43

Partial correlations between variables related to each of the three measures of parental support to use resources to make and maintain friendships reflected the inter-correlations described above. Controlling for the number of recreational activities carried out with friends reduced the relationship between the frequency of recreational activities with friends and measures of support to insignificant levels and vice versa. Similarly controlling for the impact of caring for disabled adults reduced the

43 See appendix XXIX for results of all relevant analyses
relationship between the impact of caring for other disabled children and the number of aided resource activities and vice versa. This suggests that these variables share a large amount of the variance they account for in measures of parental support to use resources to make and maintain friendships.

Qualitative information

Question 19 and 20 were open-ended. The first asked parents if there were any other obstacles to their child’s social life they wanted to share and the second asked parents if they had any ideas about ways in which services could help to promote their child’s social life. Responses to question 19 and 20 were not obtained from all parents. In total 45 (61.6%) parents responded to question 19 and 40 (54.8%) responded to question 20. In addition some parents mentioned further obstacles to their child’s social life when responding to question 20 and others mentioned ideas for service development when responding to question 19. As a result responses to question 19 and 20 were combined and examined for themes under the headings of “further obstacles to child’s social life” and “service development ideas”.

• Further obstacles to children’s social lives

The themes that emerged from parents’ responses to questions 19 and 20 on the topic of further obstacles to children’s social lives are presented in appendix XXX.

Overall, the most common (n = 40, 80%) obstacles to young people’s social lives mentioned by parents were their individual characteristics including communication difficulties (n = 9, 18%), behaviour problems (n = 5, 10%), poor daily living skills (n = 3, 6%), poor confidence levels (n = 3, 6%), a dislike of social activities (n = 4, 8%), poor social skills (n = 8, 16%), vulnerability (n = 7, 14%) and sensory difficulties (n = 1, 2%). Other obstacles included practical difficulties (n = 12, 24%) such as having to travel long distances to get to social activities or visit friends (n = 5, 10%), transport issues (n = 5, 10%) and there being insufficient organised social activities in the area (n = 2, 4%), as well as parental issues (n = 9, 18%) such as lack of support (n = 4, 8%), other caring responsibilities (n = 3, 6%), working hours (n = 1, 2%) and carer’s
own issues (n = 1, 2%). The least common yet important obstacle to emerge was the general public’s attitude towards people with disabilities (n = 6, 12%).

- Service development ideas

The themes that emerged from parents’ responses to questions 19 and 20 on the topic of service development ideas for the promotion of children’s social lives are presented in appendix XXX.

The most common service development ideas for the promotion of children’s social lives to be suggested by parents were services for groups of children (n = 28, 56%) including after school clubs for children with special needs (n = 7, 14%), after school clubs for children of mixed abilities (n = 6, 12%), after school clubs for children non-specified abilities (n = 3, 6%), educational classes for children with special needs (n = 6, 12%), weekend/holiday clubs (n = 4, 8%) and day trip clubs (n = 2, 4%). Other service development ideas put forward by parents were around practical issues (n = 8, 16%) such as providing free transport (n = 5, 10%), more information (n = 1, 2%) and more local special needs schools (n = 1, 2%). Other ideas included the need for more support (n = 7, 14%) such as one-to-one support for young people’s specific needs (n = 5, 10%), support for siblings (n = 1, 2%) and respite care (n = 1, 2%). The least common idea to be mentioned by parents was the promotion of disability issues in the general population (n = 2, 4%).

Generalisability investigation

- Meeting with parents at voluntary organisation

Ten parents of young PWLD of mixed abilities who attended a support group at a local voluntary organisation were asked to make comments about the accessibility and content of a flyer that described the results of the current study. This provoked a discussion on the topic of obstacles to young PWLD’s SWB. Parents talked about some of the issues that had been highlighted by the study’s participants and added insights that had not previously been considered.
Parents complained that there were too few organised social activities for young PWLD and that those that existed were seriously under funded. They explained that funding issues had a direct impact on the number of young people that could benefit from these services because they usually resulted in a reduced provision of transport and staffing. Parents felt transport to and from a service was essential because social clubs and activities were usually far away, started after school (3pm) and finished during the London rush hour (4-7pm). Many of them did not have private transport facilities of their own. Parents felt that staffing levels were important because the government had introduced a recommendation that each child with mobility problems should have one-to-one staff support. This meant that many social clubs and activities were now excluding young people with mobility problems. They explained that in some cases young people were being given their own funding that allowed them to bring a carer with them but this was not widespread. Parents also felt that social clubs did not always appeal to all young PWLD because they included children with a wide range of abilities.

• Results of generalisability investigation
In total 592 flyers were distributed to parents of pupils at four SNS. The IC was not able to participate in this part of the study. Forty-five (a response rate of 7.6%) were returned in the stamped addressed envelopes provided. This was a lower response rate than had been achieved with the original SWB questionnaires, which suggests that the length and complexity of the questionnaire may not have been what caused the low number of returned questionnaires. Parents’ responses to the questions included on the flyer are presented in table 4.

Table 4: Results of generalisability investigation

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>No answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do the results fit with your personal experience?</td>
<td>44</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Do you think the results reflect how things are generally?</td>
<td>43</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Did you complete a questionnaire on the social well-being of your child with learning disabilities?</td>
<td>28</td>
<td>17</td>
<td>0</td>
</tr>
</tbody>
</table>

Over a third (37.7%) of parents who returned a flyer had not previously completed a questionnaire on SWB. One of these parents did not feel the study’s results fitted with
their personal experience and one did not respond to the question about whether the results fit with how they felt things were generally.
Discussion

In this thesis an attempt has been made to explore the relationship between parents’ parenting strategies and their perceptions of their learning disabled child’s social needs and abilities. The impact of other factors - such as their beliefs about the importance of social wellbeing - on their levels of responsiveness to their child’s social needs have also been explored. A better understanding of the reciprocal nature of the ways in which these diverse factors interact should help us understand the multiplicity of levels which contribute to the social well being of a child with learning disabilities. Once disseminated, this in turn should hopefully impact upon policy and service provision.

Summary of findings

The results of the current study indicate that on average parents gave their child access to just under two-thirds of resources listed and supported them to carry out a quarter of the resource activities listed, about once a month. In addition, parents’ reports about the amount of support they give their children to use resources to make and maintain friendships were related to their perceptions of the number and frequency of recreational activities their children carry out with friends, the social impact of their children’s inappropriate personal habits, self injury, property destruction and problems speaking and the impact of caring for other disabled children, caring for adults and their own physical problems. On the other hand they were not related to their beliefs about the importance of SWB for their children’s current and future well-being, to reports about the severity of their children’s disabilities or to the presence of external support. These findings will now be discussed in relation to the literature presented in the introduction.

Findings related to research aim and questions

On average, parents reported giving their children access to just under two-thirds of resources listed in the questionnaire. This suggests that these resources were available for young people to use to make and maintain friendships and that parents were happy for their child to use them in this way. Parents also reported that on average their child carried out approximately a quarter of resource activities listed with help. There was
no difference between the number of resource activities they were reported to carry out with help and independently. This indicates that young people's need for assistance to use resources did not result in them using more or less resources than other young people. In other words helpers did not prevent young people from using as many resources as they would have liked or encourage them to use them more than they would have otherwise. Parents also reported that on average their child carried out aided and unaided resource activities about once a month. This implies that young people's need for assistance to use resources did not result in them using resources more or less often than other young people. In other words helpers did not prevent young people from using resources as often as they would have liked or encourage them to use them more often than they would have otherwise.

Parents' reports of the amount of support they gave their child to use resources to make and maintain friendships were related to their perceptions of the number and/or frequency of recreational activities they carried out. Since correlations do not infer causality there are a number of ways in which this can be interpreted. Parents may have given their child support to use more resources in response to their appraisal of the number and frequency of recreational activities their child was carrying out with friends. For example, they may have interpreted their child's level of recreational activity with friends as an indication of their level of social skill and/or of how much they liked this kind of activity. Giving their child more support to use resources to make and maintain friendships may have been a way of encouraging them to develop further skills in this domain and/or carry out more enjoyable activities. Similarly, their child might have requested more support to use resources to make and maintain friendships as a result of positive experiences carrying out recreational activities with friends. On the other hand young people may have carried out more recreational activities with friends as a result of the amount of support they were given (or requested) to use resources. For example: they may have used emailing facilities to develop friendships with people they later carried out recreational activities with; they may have used internet facilities to plan recreational activities with friends such as a trip to the cinema; they may have used public transport to carry out a recreational activity with friends such as going bowling. In reality, each of these interpretations suggests that these results support the findings reported by Gallimore et al., (1989, 1999) and Nihira et al., (1983, 1985) because they either imply that parents have
adapted their parenting strategies in response to their perceptions of their children’s strengths and weaknesses or that parents’ strategies are fulfilling their children’s needs. These researchers’ findings with regards to the reciprocal influence between parents and their children imply that all the interpretations described above may be correct and that parents and children may influence each other with regards to SWB. However, the design of the current study does not provide the longitudinal information necessary to be sure about the reciprocity of these influences.

Furthermore, parents’ reports of the amount of support they gave their child to use resources to make and maintain friendships were related to their perceptions of the impact of certain child characteristics on their child’s social life, such as destroying property, self harming, having problems speaking and displaying inappropriate personal habits. Again it is not possible to infer causality from this correlational analysis. As such, these results may indicate that parents’ assessed their child’s social life to be more negatively affected by their individual characteristics as a result of giving them less support to use resources. They may, for example, have learned more about their children’s characteristics and the way they affect their social lives when they supported them to use resources to make and maintain friendships. On the other hand the results may also indicate that parents gave their child less support to use resources as a result of their appraisal of the negative impact of their child’s individual characteristics on their child’s social life. As such, parents who reported that their child’s social life was negatively affected by their tendency to destroy property may not have wanted to give them access to certain resources for fear that they would damage them. Further, parents who reported that their child’s social life was negatively affected by their speech difficulties may have had children who had poor overall communication skills or poor social competence (Beadle-Brown et al., 2002; McCabe & Meller, 2004) and who would not have been able to use certain resources even with help. In addition, parents who reported that their child’s social life was negatively affected by their tendency to injure themselves may have felt their child was too vulnerable to use resources safely. They may also have felt that their child’s self-injury would be distressing to others and may not have wanted to expose others to it. Further, parents who reported that their child’s social life was negatively affected by their tendency to display inappropriate personal habits or self-harm may have felt their children were too severely disabled (Borthwick-Duffy, 1995) to benefit
from using resources with or without support. At any rate, if parents’ perceptions of
the social impact of any of their child’s individual characteristics influenced their
parenting, these results may also support the findings presented by Gallimore et al.,
(1989, 1999) and Nihira et al., (1983, 1985). This is because they imply that young
people’s presentations influenced parenting by affecting parents’ SWB related
expectations and aspirations for their children.

Moreover, parents’ reports of the amount of support they gave their child to use
resources were related to their perceptions of the impact of parental circumstances on
their ability to care for their child, such as caring for other disabled children, caring
for adults and their own physical problems. Those who were caring for adults or
children and felt this prevented them for doing all the things they wanted to for their
child may thus have been motivated to do more of what they could which included
supporting their child to use resources to make and maintain friendships. On the other
hand those who supported their child to use resources may have been inspired to do
more but felt limited in doing so be their responsibilities towards the adults and other
children they were caring for. Similarly, parents may have developed physical
problems or become more aware of their physical problems as a result of have to care
for their child including having to support them to use resources on a regular basis.
On the other hand they may have been motivated to support their child to use
resources on a regular basis as a result of not being able to support them or care for
them in other more physically demanding ways. These results support the suggestion
that parents’ perceptions of these do not support the hypothesis explored in the current
study that parents who perceived themselves as being limited in their ability to care
for their child with learning disabilities by their own circumstances would report
providing less support to them to use resources to make and maintain friendships.

In contrast, parents’ reports of the amount of support they gave their child to use
resources to make and maintain friendships were not related to their beliefs about the
importance of SWB for their child’s current and future well-being. These results do
not support findings reported by Musun-Miller and Blevins-Knabe (1998) who found
that parents’ beliefs about the importance of children learning certain skills were
positively correlated with their self reports of carrying out related activities with their
child. Neither do they support findings reported by Mize and colleagues (1995) who
found that parents’ beliefs about the importance of peer relations were positively correlated with the number of play experiences they arranged for their children. This may be because all parents’ rated SWB as either ‘important’, ‘very important’ or ‘extremely important’ or because other factors influence their SWB related parenting strategies more than their beliefs.

Further, parents’ reports of the amount of support they gave their child to use resources to make and maintain friendships were not related to their reports about the severity of their child’s learning disability. This suggests that parents did not provide more or less support to children with potentially more fundamental difficulties with social interactions such as children with autistic spectrum disorders (Baron-Cohen et al., 1985). It also indicates that parents did not provide more or less support to children who may have made more demands on their time in other areas (Borthwick-Duffy, 1994; Emerson et al., 1987). This was the case despite the fact that they perceived children with more severe learning disabilities to have fewer friends. This finding did not support Murray and Cornell’s (1981) theory that parents with more severely disabled children have more difficulty adapting to having a child with a learning disability and are at an increased risk of parental plegia.

Furthermore, parents’ reports of the amount of support they gave their child to use resources to make and maintain friendships were not different depending on whether or not they received external support from professional bodies, friends or family. This suggests that the presence of external support may not have protected parents from adaptation difficulties in the way it was proposed by Cnic et al., (1983). Alternatively, parents may have used the time and energy they preserved from receiving external support to encourage their child to develop in areas other than SWB.

As such the results of the current study seem to provide some evidence that parents’ SWB related parenting strategies are related to their perceptions of their child with learning disabilities’ SWB, the impact of individual characteristics on their child’s social life and the impact of their circumstances on their ability to care for their child. This appears to provide some support for research findings, reported earlier,
indicating that parents adapt their parenting strategies in response to their perceptions of their children's strengths and weaknesses and that these adaptations fulfil their children's needs (Gallimore et al., 1989, 1999; Nihira et al., 1983, 1985). However this evidence is weak and needs further investigation before it can be considered reliable. Although the level of variance in measures of parental support explained by measures of parental perceptions of their child's SWB, of the impact of individual characteristics on their child's social life or of the impact of their circumstances on their ability to care for their child was significant it was also often very low (the percentage of variance explained ranged from 4% to 26%) and not always unique. This makes it possible that there is no causal relationship between these variables and that they are related to some other linking factor not examined in this study.

Limitations
Several aspects of the study's design may have limited the value of the findings. These include the design of the questionnaire, the reliance on parents alone for the information gathered, the use of a quantitative approach rather than a qualitative approach and the way in which the sample was obtained.

The design of the questionnaire may have affected the results of the study because some of the scales may not have provided valid representations of parents' views. For example, the scale developed to measure of parents' beliefs about the importance of quality of life domains developed on the basis of Schalock's (1996) eight-domain model of quality of life may not have facilitated the measurement of subtle differences in opinion. Parents were asked to choose from six value labels to indicate how important they felt a domain indicator was for the current and future well-being of their child with learning disabilities. These value labels may not have evoked sufficiently different levels of importance to detect subtle differences in parents' opinions. This may be one of the reasons why measures of parents' beliefs about the importance of SWB were not related to measures of their SWB parenting strategies.

In addition, this scale may not have measured SWB as it is defined in this study. A factor-analysis would have indicated whether or not this was the case but was not possible because of skewed data, the nature of the scoring and the numbers of participants obtained. One of the items that related to this domain referred to social
support from family as well as friends. Another referred generally to social interactions. It may be that parents rated these items with family in mind rather than friends. They may also have interpreted items related to other domains as being relevant to SWB. Results indicating that parents’ ratings of the importance of social inclusion were positively related to frequency of contacts with friends provide evidence for this. Items that related to this domain referred to acceptance and respect. These concepts are also clearly relevant to positive social relationships and interactions.

Furthermore, instructions for the scale developed to measure the amount of support parents give their child to use resources to make and maintain friendships may not have been specific enough. They asked parents to indicate how often their child carried out the activities listed in the scale. They could have asked them to indicate how often their child carried out the activities for social purposes. Although it is perhaps difficult to imagine for what other purposes a child might send a text message or an email it is not so difficult to imagine other reasons for them using public or private transport. Parents may have included trips to and from school in their estimations of how often their child used public or private transport. However, if this were the case results would be expected to show that most children used resources every day. In reality they indicate that only one child carried out aided resource activities every day and only four carried out unaided resource activities every day. This suggests that parents did not include trips to and from school in their reports of how often their child used resources to make and maintain friendships.

Parents’ responses to open-ended questions revealed that not all relevant issues had been addressed in the questionnaire. They identified other individual characteristics that impacted on their child’s SWB. These included poor daily living skills, poor confidence levels and a dislike of social activities. They also identified some practical issues that impacted on their child’s SWB. These included having to travel long distances to get to social activities or visit friends, transport issues and there being insufficient organised social activities in the area. They also mentioned a societal issue that impacted on their children’s SWB; the general public’s attitude towards people with disabilities. Including these factors might have improved the richness of the findings. On the other hand many of the issues included in the questionnaire were
also raised in parents’ qualitative responses. This adds to the validity of the study and its results.

The study’s reliance on one source of information (i.e. the parents) could also have affected the results by increasing the strength of correlations. As mentioned in the introduction Pike and colleagues (1996) showed that these kinds of within-informant correlations can be misleading. Young people could have been given a specially designed questionnaire or been interviewed about their friendships, social activities and use of resources to make and maintain friendships. School staff could also have been asked to participate in these ways. However, this would have meant only including young people who could communicate well enough to complete a questionnaire or answer questions. Also, school staff were unlikely to have the time to participate and might not have known about young people’s friendships and social activities outside of school.

A further potential limitation of this study is the representativeness of the sample. As mentioned in the method section the overall response rate was quite low and almost no participants took up the offer of support to complete the questionnaire. This suggests that parents who participated in the study were able to complete the questionnaire independently and that the length and complexity of the questionnaire may have prevented less able parents from participating. In addition, parents’ reports about the severity of their child’s disability suggested that those with severely disabled children were better represented in the sample of parents that participated in the current study than they were in most participating schools. This raised concerns about how representative the sample was of the wider community of parents of PWLD and therefore how generalisable the results were. As a result an investigation took place that involved sending a summary of results, deemed accessible by a group of parents of young PWLD of mixed abilities, to parents and asking them whether they matched their experience and/or how they felt things were generally. The majority of respondents stated that they felt the results matched their personal experience including over a third that had not previously completed a SWB questionnaire. In addition the majority of respondents stated that they felt the results fit with how they felt things were generally including over a third that had not previously completed a questionnaire. Moreover, even fewer parents responded to this
very brief measure than had responded to the questionnaire suggesting that the original response rate was not caused by the length and complexity of the questionnaire and that the study's results were representative of the experience of parents of young PWLD from each of the six participating schools.

As mentioned in the introduction a qualitative rather than a quantitative design could have been used to explore the factors that influence the amount of support parents give their learning disabled children to develop SWB. Disadvantages of using a quantitative method included not being able to get in depth information about people's experiences, limiting the involvement of parents with learning disabilities of their own and getting socially desirable responses. Although efforts were made to overcome some of these issues such as including open-ended questions in the questionnaire and conducting a generalisability investigation, not all could be directly addressed. Parents may still have responded in a socially desirable way. They may have reported that their child had more friends, saw their friends more regularly, carried out more activities with friends than they really do. However if this were the case, results would be expected to indicate that the children who were the focus of the questionnaires had large number of friends, who they saw regularly and carried out many activities with on a regular basis. Instead they indicate that almost a third of all children had no friends at all and that almost two thirds never carried out activities with friends. On the other hand parents may be more likely to respond in a socially desirable way about themselves than about their children. They may have reported that they provide their child with more support to use resources to make and maintain friendships than they really do. However if this were the case, results would be expected to show that parents regularly supported their child to use many resources. In reality they indicate that over a third of parents do not support their child to carry out any resources activities and that over a third support their child to carry out resource activities on average only a few times a year. These results are not consistent with the socially desirable image of supportive parents and happy fulfilled children and suggest that participants may have been honest in the responses they gave.

Further research
Further research in this area might benefit from obtaining information from multiple sources including young PWLD and professionals that work with them. If a
quantitative approach was used, the questionnaire might be improved by making the adjustments to scales described above. In addition items might be added to the questionnaire to include issues revealed by parents’ responses to open-ended questions. Items that proved to be less useful, such as those regarding recreational activities carried out with families and alone, could be removed to reduce the length of the questionnaire. Alternatively a qualitative approach could be used which could include interviews with parents, young people and professionals.

Further research in this area could also focus on the variety and quality of resources available to young PWLD to enable them to develop SWB. This could include an investigation into the ways these resources are managed, distributed and funded by different organisations such as local government and charitable foundations. It could also include a comparison between the resources available to different ethnic and socio-economic groups.

Implications
The results of analyses based on this study’s research questions are probably too weak to have immediate implications for clinical practice or theory. On the other hand information provided by parents about the level of their children’s SWB and the factors that impact on their children’s SWB should not be ignored and adds to the growing body of knowledge. A large proportion of the young people who were the focus of this study were reported to have no friends and did not carry out activities with friends. Some parents felt that this was because their children exhibited challenging behaviours or had communication difficulties. Others felt that this was because organised activities were difficult to access. Yet others felt that it was because of the general public’s attitude towards PWLD. These are all issues that professionals working with PWLD can do something to address.

Conclusion
The concept of a reciprocal relationship between parents and their children outlined by Bell (1968) and supported by current research findings (Gallimore et al., 1989, 1999; Nihira et al., 1983, 1985; O’Connor et al., 1998) inspired the present studies’ investigation into the relationship between parents’ perceptions of their children with learning disabilities’ social strengths and weaknesses and their SWB related parenting
strategies. Evidence was found to support the idea that these parenting strategies are related to parents’ perceptions of their children’s social strengths and weaknesses and the way their own circumstances limit their ability to care for their child. This highlights the usefulness of looking at the dynamic interactions of the parent-child dyad rather than focusing on one direction of influence.

It took a lot of time and hard work to gather the views of a sufficient number of parents and ensure they were representative of the views of the larger community of parents of young PWLD. However, this process allowed the researcher to meet and be inspired by many parents and professionals who do what they can to provide young PWLD with optimal life experiences on a day-to-day basis. This research project sought to support these individuals in their efforts by contributing to the wider understanding of how young PWLD are parented. It may actually do so by highlighting the rewards and difficulties of exploring the lives of young PWLD and their families and the importance of taking into account the complexities and reciprocities of the parent-child relationship in this context.
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Office for Standards of Education: [www.ofsted.gov.uk](http://www.ofsted.gov.uk)


Appendix I: Stages of grief (Bicknell, 1983)

- Shock: emotional refrigeration or procrastination
- Panic: catastrophic thinking
- Denial: refusal to accept either the child or the diagnosis
- Grief: experience of pain in response to what has happened
- Guilt: accepting blame for what has happened
- Anger: attributing blame for what has happened
- Bargaining: looking to share responsibility with others
- Acceptance: when the pain subsides and parents begin to love their child and come to terms with reality.
- Ego-centred work: making plans
- Other-centred work: helping others
Appendix II: Definitions

Challenging Behaviour
The most widely accepted definition of challenging behaviour is:

“behaviour of such an intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities.”
(Emerson et al., 1987)

In this sense challenging behaviour includes all behaviours that put the person or those around the person at risk of physical harm and all behaviours that are sufficiently socially unacceptable as to cause exclusion from mainstream society. As this suggests, there are a huge variety of behaviours that can be described as challenging behaviours. In five broad categories they include aggression to others, self-injurious behaviour, damage to the environment, inappropriate personal behaviours such as smearing and spitting and resistant behaviours such as stereotyped or repetitive behaviours. In essence it is the level of social disruption caused by a behaviour that determines whether it is defined as challenging.

Hearing Impairment

Hearing impairment is when the hearing is affected by a disease, disorder or injury. Deafness is a profound loss of hearing. Leading charity, the RNID, estimates that there are between eight and nine million deaf and hearing impaired people in the UK. This number is expected to rise as the number of people over the age of 60 increases.

Hearing loss can be present at birth (deaf or hard of hearing people) or develop in childhood or adulthood (deafened people). It occurs for a large number of reasons, which can be categorised into conductive and sensori-neural.

Conductive means that sound coming into the ear is blocked in some way from travelling to the inner ear. Conductive causes include:
Major Research Project

- Middle ear infections,
- Glue ear,
- Wax blockage,
- Eardrum injury,
- Otosclerosis (a disorder of the middle ear),
- and Rheumatoid arthritis.

Sensorineural causes are ones where the pathway the sound travels along is damaged. These include:

- Age-related hearing loss,
- Acoustic trauma (physical damage to the ear),
- Viral infections such as mumps or measles,
- Meniere's disease,
- Acoustic neuroma (a non-cancerous growth near the hearing nerves),
- Meningitis,
- Encephalitis,
- Multiple sclerosis,
- Brain tumours,
- and Stroke.

Information from NHS Direct (www.nhsdirect.nhs.uk)

Learning Disability

The definitions of “learning disability” given by the World Health Organisation (International Classification of Diseases and Related Health Problems - 10th revision (ICD-10), 2003), the American Psychiatric Association (Diagnostic and Statistical Manual for Mental Disorders - Fourth Edition (DSM IV), 1994), the Department of Health (Valuing People, 2001) and the British Psychological Society (BPS, 2001) are slightly different but all include the presence of the following:

- A significant impairment of intellectual functioning and
- A significant impairment of adaptive behaviour/social functioning
- Impairments (described above) that are present before adulthood
A “significant impairment of intellectual functioning” is usually defined as an intelligence quotient (IQ) of more than two standard deviations below the mean for the general population (BPS, 2001). This is an IQ of less than 70 on recognised tests of IQ such as the Wechsler Adult Intelligence Scale- 3rd UK edition (Wechsler, 1999) or the Wechsler Intelligence Scale for Children – 3rd edition (Wechsler, 1991). A “significant impairment in adaptive behaviour/social functioning” usually refers to a lack of independent living skills including communication, socialisation and domestic skills. Although the impact of these characteristics on SWB is not directly examined in the current study, it is indirectly examined through the impact of severity of disability. As a result relevant research is reviewed below.

**Visual Impairment**

Visual impairment is used to describe people who are blind or partially sighted, as opposed to long or short-sighted. A person with a visual impairment has some loss or distortion of their vision. Depending on how severe the sight loss is, the conditions are usually known as partial sightedness or blindness.

Partial sightedness: A person with partial sight or severe low vision has a serious loss of sight but is not blind. This has been defined by the World Health Organisation as a person who cannot clearly see how many fingers are being held up at a distance of 6 metres or less (even with their glasses or lenses on).

Blindness: A person who is blind has very severe sight loss and is unable to clearly see how many fingers are being held up at a distance of three metres or less (even with their glasses or lenses on). However, they may still have some degree of vision.

Information from NHS Direct (www.nhsdirect.nhs.uk)
Appendix III: Barriers to Social Well-being

Impaired intellectual functioning

Difficulties in intellectual functioning are associated with school achievement and Lindzey and Byrne found some evidence to suggest that such achievement affects children’s social status (as cited in Bryan, 1976). Alternatively, impaired intellectual functioning may affect the style of friendships young PWLD seek and offer. Heiman (2000) found that adolescent students with disabilities valued helpfulness, fun and entertainment in friendships whereas non-disabled students valued intimacy. Concepts of intimacy and reciprocity may not be developed in young PWLD. Young PWLD may also achieve less intimacy because they are unable to complete the complex processes involved in seeking support. Geisthardt and Munsch (1996) found that students with learning disabilities were less likely to seek support from peers because they did not recognise their need for support or have the skills to seek it.

Impaired intellectual functioning can also affect the social functioning of young PWLD. Kronick (1978) suggests that these young people have difficulties in perceiving the way social interactions are organised and generalising from their experiences. This makes it difficult for them to assess social situations and ascertain the most appropriate social behaviour. Indeed, adolescents with learning disabilities are often found to have difficulties labelling their own and others’ affective states (Wiig & Harris, 1974; Bryan, 1974) and reading implicit social cues that help determine appropriate social behaviour (Bryan & Pflaum, 1978). Unfortunately social functioning impairments like these tend to be stable over time (Beadle-brown et al., 2002, 2005) and are frequently associated with poor SWB in young PWLD (Nowicki, 2003; Orsmond et al., 2004).

Another way in which intellectual impairment can affect social functioning is when it is in the form of a deficit of theory of mind. Theory of mind refers to a person’s ability to understand others as personal agents with beliefs and desires. Baron-Cohen and colleagues (1985) presented evidence that the difficulties associated with autism, namely impaired social interaction, communication and imagination could be explained by a specific deficit of theory of mind. This suggests that theory of mind is integral to social functioning.
Challenging behaviour

PWLD can have behavioural problems that interfere with their ability to develop and maintain social relationships. These behaviour problems are often referred to as challenging behaviours. The most widely accepted definition of challenging behaviour is:

“behaviour of such an intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities.” (Emerson et al., 1987)

In this sense challenging behaviour includes all behaviours that put the person or those around the person at risk of physical harm and all behaviours that are sufficiently socially unacceptable as to cause exclusion from mainstream society. As this suggests, there are a huge variety of behaviours that can be described as challenging behaviours. In five broad categories they include aggression to others, self-injurious behaviour, damage to the environment, inappropriate personal behaviours such as smearing and spitting and resistant behaviours such as stereotyped or repetitive behaviours. In essence it is the level of social disruption caused by a behaviour that determines whether it is defined as challenging.

The prevalence of challenging behaviour in PWLD seems to increase during childhood, reaching a peak between the ages of 15 and 34 and declining from then on. Overall these behaviours are found in 12.4% of children with learning disabilities in the UK (Qureshi & Alborz, 1992). They tend to positively correlate with degree of intellectual impairment (Borthwick-Duffy, 1994). The consequences for the person who exhibits challenging behaviours include being placed out of home earlier in life (Lowe et al., 1998), being excluded from services (Emerson et al., 1987), social exclusion and abuse (Felce et al., 2000). This is partly explained by the consequences of these behaviours for people around those who exhibit them. For carers the consequences include potential physical harm, a significantly increased burden of care (Emerson et al., 1987), significant stress (Emerson, 1995) and high healthcare and social costs (Felce et al., 2000). For peers they include perceiving children with learning disabilities who exhibit challenging behaviour as some of the most aggressive and disruptive students in integrated schools (Farmer et al., 1999).
Thus challenging behaviour may cause children to be rejected by their carers and their peers because it affect carers' motivation to care for them, perhaps including their motivation to support them to develop social wellbeing, and because it affects peers' motivation to build and maintain relationships with them.

**Sensory impairments**

PWLD may also suffer from sensory impairments that could interfere with their social interactions. Sensory impairments are a lot more common in PWLD than in the general population. A national survey in the UK found that 48% of PWLD had a single sensory impairment of at least moderate severity and 18% had dual sensory impairment (Office of Population Censuses and Surveys, 1988). In addition, a recent review of local surveys suggests that, on average, one in three PWLD have a sensory impairment (Harries, 1991). These include hearing and visual difficulties.

**Hearing impairment**

Surveys of PWLD living in the community and in hospital suggest that approximately 40% have moderate to severe hearing loss and only about 20-25% have normal hearing (Yeates, 1995). Research on the social relationships of hearing impaired adolescents in mainstream schools suggests that they often have difficulties building relationships with hearing peers (Davis, 1989). Similarly to adolescents with learning disabilities, non learning disabled hearing impaired adolescents in these settings have been found to experience loneliness, rejection and social isolation (Foster, 1988; Mertens, 1989). Hearing impaired children seem to have difficulty relating to their hearing peers and prefer building relationships with hearing-impaired peers (Stinson et al., 1996). This may be because hearing-impaired people share difficulties and methods of communication (Stinson et al., 1996), because they have poorly developed theory of mind when pre-lingually deaf (Petersen & Siegel, 1995) or because hearing adolescents can have negative attitudes towards hearing-impaired adolescents (Meadow, 1980).

There is very little research on the social relationships of adolescents with learning disabilities and hearing impairment in special needs educational settings. Adolescents
with learning disabilities and hearing impairment may be more likely to build relationships with hearing peers when these peers have other disabilities. In this situation hearing peers may not have negative attitudes towards hearing-impaired adolescents because they are disabled themselves. They may also have other communication difficulties that help them to relate to hearing-impaired children. On the other hand adolescents with learning disabilities and hearing-impairment may be just as unlikely to build relationships with hearing peers who have learning disabilities. The presence of additional disabilities may make communication between these two groups even more challenging. There is also very little research on the social relationships of adolescents with learning disabilities and hearing impairment in integrated educational settings. However, research reviewed above which describes the difficulties experienced by adolescents with learning disabilities and adolescents with hearing impairments in integrated educational settings suggests that adolescents with learning disabilities and hearing-impairment are unlikely to have good social wellbeing in these settings.

Visual impairment
Surveys suggest that approximately 40% of PWLD have a visual impairment (Warburg, 2001; Flannaghan et al., 2003). Visual impairments seem to be more common in people with specific conditions such as Down’s syndrome and in people with more severe learning disabilities (VanSchrjenstein–Lantman–de Valk, 1998). Research on the social relationships of children with visual impairments suggests that they encounter difficulties with social interaction and integration (MacCuspie, 1992). They tend to be more socially isolated and have smaller social networks than their sighted peers (Huure & Aro, 1998; Kef, 1997). This may because of the negative attitudes of their sighted peers (Hodges & Keller, 1999) or because they can have poorly developed theory of mind (Pring & Dewart, 1998).

There is very little research on the social relationships of adolescents with learning disabilities and visual impairment in special needs or integrated educational settings. However, research reviewed above which describes the difficulties experienced by adolescents with learning disabilities and adolescents with visual impairments in both
these educational settings suggests that adolescents with learning disabilities and visual impairment are unlikely to have good social wellbeing in these settings.

Visual and hearing impairments may thus create additional social difficulties for young PWLD by affecting the nature and quality of their communication, the development of their social cognition and the way others perceive them.

**Mobility problems**

Many PWLD also have physical disabilities. People who have severe learning disabilities often have an associated disorder, which affects their mobility (Emerson et al., 2001). Motor impairments associated with damage to the central nervous system occur in 20-30% of PWLD (Mclaren & Bryson, 1987).

Research suggests that in the general population, motor impairment during childhood can result in anxiety problems amongst male children between 11 and 16 years of age (Sigurdson et al., 2002). This may be because at that age a lot of social interaction takes place around physically demanding activities such as sports and outdoor play. Anxiety in itself is likely to affect young male adolescents' ability to interact socially with physically disabled and non-physically disabled peers in any educational setting. In addition, government legislation advises services to provide additional support for PWLD who are dependent on technology.

**Communication difficulties**

It has been suggested that most children with learning disabilities have some difficulties with communication (Emerson et al., 2001). Others have suggested that approximately 50% of PWLD have significant difficulties with communication (Enderby & Davies, 1989). Such difficulties include expressive communication difficulties, like a poor grasp of language (Clarke-Kehoe & Harris, 1992) as well as receptive communication difficulties, like poor understanding (Banat et al., 2002). Some people with learning difficulties and communication difficulties also have impairments of social competence (Beadle-Brown et al., 2002; McCabe & Meller, 2004). However this has been related to educational setting in some studies (Farmer, 2000) and impaired executive function in other studies (Marton et al., 2005).
Nevertheless, many people with learning difficulties and communication difficulties have behavioural problems, which are known to have negative impact on social relationships (Hummel & Prizant, 1993). The impact of communication difficulties on SWB is examined in the current study.

Parental factors

Evidence suggests that the parents of PWLD play a major role in orchestrating their social lives (Krauss et al., 1992; Seltzer & Krauss, 1999; Seltzer et al., 2002). This implies that the social wellbeing of young PWLD may lie in the hands of their parents. However, research shows that in some cases parents do not provide the support required for their children to develop friendships. Smith and Sykes (1981) found that parents were aware that their children had few friends, even spoke with regret about their children’s lack of friends and hobbies, but did not make efforts to tackle these issues. In another study 60% of mothers admitted that their children’s best friends were immediate or extended family. Although they wanted them to have other friends, they all expressed a fear of their children being taken advantage of (Lehmann & Baker, 1995). On the other hand, research shows that other young PWLD are not given the freedom to plan social activities for themselves. Over half of Zetlin and Murtaugh’s (1988) sample spent weekends and holidays alone or with family who acted as chaperones rather than friends. They found that this was because their parents did not let them plan their own spare time. Similarly, in Orsmond and colleagues’ (2004) study, adolescents with autism were more likely to take part in social and recreational activities when their mothers took part in similar activities.

This may be because some parents have failed to adapt to having a child with disabilities and have alternative ways of prioritising their children’s needs. They may thus be overprotecting, infantilising or rejecting their child. Alternatively, some parents may simply not believe that SWB is important for their child’s current and future well-being. This belief may have developed in response to their perception of their child’s difficulties in this area or in response to socio-cultural ideas about wellbeing in PWLD. Finally, parents’ may be underestimating their child’s abilities such as abilities to organise a social activity or abilities to make and maintain friendships.
The social model of disability

Although it is not included in the definition of learning disability, many people with disabilities believe that they share another common characteristic that prevents them from having ‘normal’ social relations and interactions. That is the experience of being discriminated against by the non-disabled majority. This experience was described in the social model of disability put forward by the Union of the Physically Impaired Against Segregation (UPIAS, 1976). In this model ‘impairment’ is distinguished from ‘disability’ in the sense that:

- Impairment is described as “the functional limitation within the individual caused by physical, mental or sensory impairment” and
- Disability is described as “the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers” (Disabled People’s International - DPI, 1982).

This suggests that people with disabilities are not prevented from leading ‘normal’ lives by their own characteristics or impairments but by a society that does not take their needs into account and does not therefore offer them equal opportunities. With regards to young people with learning disabilities and social well-being, equal opportunities might include being supported to travel to and from social events, or being supported to use the telephone to make social contacts.
## Appendix IV: Parents' Education

Table 1: Parents' highest level of education

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<tr>
<th>Qualification</th>
<th>Number</th>
<th>Percentage of total sample</th>
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<tbody>
<tr>
<td>None</td>
<td>12</td>
<td>16.4</td>
</tr>
<tr>
<td>GSCE</td>
<td>11</td>
<td>15.1</td>
</tr>
<tr>
<td>A levels</td>
<td>15</td>
<td>20.5</td>
</tr>
<tr>
<td>Diploma</td>
<td>13</td>
<td>17.8</td>
</tr>
<tr>
<td>Degree</td>
<td>4</td>
<td>5.5</td>
</tr>
<tr>
<td>Post Grad Degree</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>No response</td>
<td>17</td>
<td>23.3</td>
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</table>
Appendix V: Borough Information

Table 1: Deprivation, Unemployment and Ethnicity in Borough 1 (ONS, 2001)

<table>
<thead>
<tr>
<th></th>
<th>Local Figures</th>
<th>National Mean for England and Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deprivation (April 2001)</td>
<td>Ranked 41st out of 351*</td>
<td>N/A</td>
</tr>
<tr>
<td>Employment (June-Aug 2004)</td>
<td>66%</td>
<td>75%</td>
</tr>
<tr>
<td>Ethnicity (April 2001):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White (inc British, Irish, other)</td>
<td>77.11%</td>
<td>91.31%</td>
</tr>
<tr>
<td>Mixed (inc, White and Black Caribbean, White and Black African, White and Asian)</td>
<td>2.73%</td>
<td>1.27%</td>
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<tr>
<td>Asian or Asian British (inc Indian, Pakistani, Bangladeshi, other Asian)</td>
<td>6.78%</td>
<td>4.37%</td>
</tr>
<tr>
<td>Black or Black British (inc Caribbean, African, other Black)</td>
<td>11.08%</td>
<td>2.19%</td>
</tr>
<tr>
<td>Chinese</td>
<td>2.29%</td>
<td>0.86%</td>
</tr>
<tr>
<td>Other Ethnic Group</td>
<td>1.11%</td>
<td>0.42%</td>
</tr>
</tbody>
</table>

*The most deprived Local Authority is indicated by a rank of 1.

Table 2: Deprivation, Unemployment and Ethnicity in Borough 2 (ONS, 2001)

<table>
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<tr>
<th></th>
<th>Local Figures</th>
<th>National Mean for England and Wales</th>
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<tr>
<td>Deprivation (April 2001)</td>
<td>Ranked 238th out of 351*</td>
<td>N/A</td>
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<tr>
<td>Employment (June-Aug 2004)</td>
<td>80%</td>
<td>75%</td>
</tr>
<tr>
<td>Ethnicity (April 2001):</td>
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<td></td>
</tr>
<tr>
<td>White (inc British, Irish, other)</td>
<td>91.59%</td>
<td>91.31%</td>
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<tr>
<td>Mixed (inc, White and Black Caribbean, White and Black African, White and Asian)</td>
<td>1.87%</td>
<td>1.27%</td>
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<tr>
<td>Asian or Asian British (inc Indian, Pakistani, Bangladeshi, other Asian)</td>
<td>2.55%</td>
<td>4.37%</td>
</tr>
<tr>
<td>Black or Black British (inc Caribbean, African, other Black)</td>
<td>2.91%</td>
<td>2.19%</td>
</tr>
<tr>
<td>Chinese</td>
<td>1.08%</td>
<td>0.86%</td>
</tr>
<tr>
<td>Other Ethnic Group</td>
<td>0.47%</td>
<td>0.42%</td>
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</table>

*The most deprived Local Authority is indicated by a rank of 1.
### Table 3: Deprivation, Unemployment and Ethnicity in Borough 3 (ONS, 2001)

<table>
<thead>
<tr>
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<th>Local Figures</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Deprivation</strong> (April 2001)</td>
<td>Ranked 212th out of 351*</td>
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<td><strong>Employment</strong> (June-Aug 2004)</td>
<td>81%</td>
<td>75%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong> (April 2001)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White (inc British, Irish, other)</td>
<td>91.39%</td>
<td>91.31%</td>
</tr>
<tr>
<td>Mixed (inc, White and Black Caribbean, White and Black African, White and Asian)</td>
<td>1.32%</td>
<td>1.27%</td>
</tr>
<tr>
<td>Asian or Asian British (inc Indian, Pakistani, Bangladeshi, other Asian)</td>
<td>3.38%</td>
<td>4.37%</td>
</tr>
<tr>
<td>Black or Black British (inc Caribbean, African, other Black)</td>
<td>2.86%</td>
<td>2.19%</td>
</tr>
<tr>
<td>Chinese</td>
<td>1.05%</td>
<td>0.86%</td>
</tr>
<tr>
<td>Other Ethnic Group</td>
<td>0.34%</td>
<td>0.42%</td>
</tr>
</tbody>
</table>

*The most deprived Local Authority is indicated by a rank of 1.
Appendix VI: Questionnaire
This questionnaire will ask you for information about yourself, your family and your child with learning disabilities. Please complete a questionnaire for the oldest child with learning disabilities (up to 19 years of age) that you care for. If you have any questions about the questionnaire or would like some help, please feel free to contact me:

Emilie Cassell
Department of Clinical Psychology
University of Surrey
Guildford
Surrey
GU2 7XH
Tel: 01483 259441
Email: psm2ec@surrey.ac.uk

1. Are you: Male □ Female □
2. What is your age? _____
3. What is your highest education qualification? _____________________
4. Please indicate which term best describes how you are related to the young person with learning disabilities who is the focus of this questionnaire by ticking the appropriate box:

   Biological parent □
   Adoptive parent □
   Foster parent □
   Carer □
   Other □
5. Please indicate how much each of the factors below affect your ability to care for this young person by circling one of the numbers on the following scale:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doesn’t apply</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family income</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Working hours</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Caring for children other than the young person who is the focus of this questionnaire</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Caring for children with disabilities or long-term health issues other than the young person who is the focus of this questionnaire</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Caring for adults with disabilities or long-term health issues</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Own physical health issues</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Own emotional issues</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

About Your Child with Learning Disabilities

6. How old is the young person who is the focus of this questionnaire? ______

7. Are they: Male □ Female □

8. Does another adult/organisation contribute to the care of this young person?
   Yes □ No □

9. If yes, please give details: __________________________________________

10. Please tick the term that you feel best describes this young person’s learning disability:
    Very Mild □ Mild □ Moderate □ Severe □ Very severe □

11. Does this young person have an Educational Statement of Need?
    Yes □ No □
12. If so, please tick the term that is used to describe their learning disability on this statement:  
Very Mild □  Mild □  Moderate □  Severe □  Very severe □

13. Using the scale below please rate how much each of the factors described interferes with your child’s social life by circling one of the numbers:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>doesn’t apply</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incontinence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Destruction of property</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inappropriate personal habits (e.g. spitting)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self Injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems speaking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical aggression towards others</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems understanding what is said</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Makes disturbing noises (e.g. shouting)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temper tantrums</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Requires constant attention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-social behaviour</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
14. **Please rate how important you feel the factors described below are for the current and future well-being of your child by circling one of the numbers on the following scale:**

<table>
<thead>
<tr>
<th>Factor</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling safe</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having close personal relationships</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Being independent</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Being accepted by others</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having privacy</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having enough money</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Being in good health</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Being happy</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having choices</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having support from friends and family</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having access to leisure activities</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having access to education</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Being free from stress</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having a valued role in society</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having friends</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Owning own home</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having personal goals</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having the right to vote</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Having skills</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Being mobile</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>---------------------------</td>
<td>-------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practising a religion</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living in the local community</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being employed</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having social interactions</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having a healthy diet</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having possessions</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being respected</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being competent</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having access to information about rights</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having meaningful things to do</td>
<td>0 1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
15. Please indicate how often your child carries out the activities described below by circling one of the numbers on the following scale:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>A few times a year</td>
<td>About once a month</td>
<td>A few times a month</td>
<td>A few times a week</td>
<td>About once a day</td>
<td></td>
</tr>
<tr>
<td>Goes to a restaurant alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a restaurant with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a restaurant with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Hangs out with friends in the local area</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a friend’s house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Stays the night at a friend’s house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Has friends come to your home</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Has friends stay the night</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a relative’s house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Stays the night at a relative’s house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes out to listen to live music alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes out to listen to live music with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes out to listen to live music with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to the pub alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to the pub with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to the pub with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a social club</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Takes part in a team or group sports (e.g. football)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a music or drama club</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes bowling alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes bowling with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes bowling with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to bingo alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to bingo with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to bingo with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to parties</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Activity</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>------------------------------------------------------</td>
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<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Goes to clubs/discos alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to clubs/discos with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to clubs/discos with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes on day trips alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes on day trips with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes on day trips with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to the cinema alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to the cinema with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to the cinema with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to the theatre alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to the theatre with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to the theatre with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to concerts alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to concerts with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to concerts with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes out to watch sports alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes out to watch sports with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes out to watch sports with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a museum or place of interest alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a museum or place of interest with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a museum or place of interest with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a Fun fair or amusement park alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a Fun fair or amusement park with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a Fun fair or amusement park with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to a play scheme</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to an after school club</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Takes part in individual sports (e.g. swimming) alone</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Takes part in individual sports with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Takes part in individual sports with family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to an out of school music/ drama lesson</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Goes to an out of school lesson</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
16. Please indicate which of the resources described below your child has access to by circling one of the numbers on the following scale:

<table>
<thead>
<tr>
<th>Resource not available</th>
<th>Does not have access</th>
<th>Uses with help</th>
<th>Uses independently</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home telephone</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobile telephone</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emailing facilities</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet access</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stamps, cards, paper so can send mail</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public transport</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private transport</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

17. Please indicate how often your child carries out the activities described below by circling one of the numbers on the following scale:

<table>
<thead>
<tr>
<th>Activity</th>
<th>0 1 2 3 4 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Makes personal phone calls</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Sends a text message</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Sends an email</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Accesses an internet chat room</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Uses MSN Messenger on a computer</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Uses public transport</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Uses private transport</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Sends a letter/card</td>
<td>0 1 2 3 4 5</td>
</tr>
</tbody>
</table>
18. Place each person who is important to your child in one of the three concentric circles on the next page, indicating how they are related and how often they see each other¹:

**In the Inner Circle:** place those to which they are closest and which they love the most and who love them the most.

**In the Middle Circle:** place those to which they are not quite so close but who are still really important people who they like or love, but not quite as much as the people in the first circle.

**In the Outer Circle:** place those to which they are not quite as close to as the others but are still important people they really love or like but not quite as much as the people in the middle circle.

Examples are provided.

¹ This question is based on the work of Levitt, Guacci-Franco & Levitt (1993)
1. Neighbour, twice a week.
2. Mum, every day
3. School friend, weekdays
19. Are there any other obstacles to your child’s social life you would like to tell us about?

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

20. Do you have any ideas about ways in which services could help you to promote your child’s social life?

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

Thank you very much for completing this questionnaire. Please feel free to add any comments about the questionnaire at the bottom of this page.

When you have finished, send this questionnaire and the signed consent form to Emilie Cassell in the stamped addressed envelope provided.
Appendix VII: School Covering Letters

2005

Dear Parent/Carers,

Re: Research on parents' views about the social wellbeing of their child with learning disabilities

I am writing to you to ask you to support yourselves and other parents who have special needs by completing this questionnaire. We can also arrange and hold a parent group meeting to support this project.

The project should help identify areas for development in local health and social services that can support young people and their parents/carers.

Many of you tell me you want more support, outside of school so here is an opportunity to let researchers know what you need.

Any queries about this please let us know.

Thank you for all your help.

Yours sincerely

2005

Dear Parent / Carer

You have been invited to participate in a research project. The school has always supported research that could help meet the needs of young people and their families.

I would be very grateful if you could take the time to complete the enclosed questionnaire.

Please do not hesitate to contact me if you have any concerns or questions about either the questionnaire or the enclosed information.

Yours sincerely
Dear Parent/Carer

I am writing to ask you to support a research project on parents' views about the social well-being of their sons and daughters who have learning needs.

Please complete the consent form and questionnaire enclosed, and return it in the SAE provided.

If you would like to have help with any part of this, then Emilie, who is running the research project, will be available here at the Campus on:

Monday  14\textsuperscript{th} November  10.00 - 12.00  
Wednesday  16\textsuperscript{th} November  4.00 - 6.00  

You can also ring Emilie on the number she's given.

I hope you can help.
Do you want to take part in a research study? This document will help you decide. Please take time to read it and talk to other people about it. If you want more information or if there is something you don’t understand, you can talk to me, Emilie Cassell. I am a Trainee Clinical Psychologist at the University of Surrey. This research is part of my doctorate. My contact details are at the end of this document.

What is the research about?
This research is about children with learning disabilities. More specifically it is about their social life and their parents’ views about it.

The study will be finished in July 2006.

Why are you asking me?
You are being asked to take part because you are the parent of a child with learning disabilities. All the parents of children with learning disabilities aged between 11 and 19 at this school will be asked.

Do I have to take part in the research?
No. It is up to you. If you decide to take part you need to sign the consent form, complete the questionnaire and use the stamped addressed envelope provided to post them back to me. If you do not wish to take part please return the pack to the school. If you decide to take part and then change your mind, you can stop at any time. Just let the school know. You do not need to give a reason. The standard of service you or your child gets from the school will not change if you decide not to take part or if you decide to stop taking part.
What should I do if I want to help with the research?
If you decide to take part you should sign the consent form included in this pack. Signing the consent form means you think your son/daughter is happy for you to take part, you are happy to take part and you understand what this involves. You should then complete the questionnaire included in this pack. The questionnaire takes about 25-30 minutes to complete. I can help you complete it if you want me to. Once you have finished the questionnaire and signed the consent form you should return them both to me in the stamped addressed envelope included in this pack. You should keep this information sheet somewhere safe.

Are there any reasons why I might not want to take part?
Most people who complete the questionnaire will not find it upsetting. However if you do find it upsetting, you can contact one of the services on the Local Support Services sheet attached.

Are there any benefits to taking part?
Taking part in this study will not directly help you or your child. However, the information we get from this study will help professionals and families caring for children with learning disabilities in the future.

Will my involvement in this study be kept confidential?
All the information collected about you and your family during the study will be kept strictly confidential. I will only share the information you give me with other people if I am worried about your safety, the safety of your child or the safety of other people. The questionnaire you complete will not ask you for your name. It will have a number on it and I will be the only person able to link that number with your name. I need to be able to link that number with your name so that I can tell which questionnaire to remove from the study if you decide to stop taking part. The school will not see the completed questionnaires. The completed questionnaires and consent forms will be kept in a locked cupboard and will only be seen by the research workers. Questionnaires completed by people who later decide to stop taking part will be shredded.

What will happen to the results of the research study?
The results of the study will be presented in a report. The results for everyone who takes part will be grouped together. There will be no names in the report. That means that no one will be able to tell that information about you and your child has been used in the research. The report forms part of my doctorate qualification in Clinical Psychology. The course examiners will see the report. A copy of the report will also
be available for parents at the school. The report might also be published in a journal.

Who is organising and funding the research?
The research is not funded. No one is being paid to do this research. The research is part of my doctorate.

Who has reviewed the study?
The study has been reviewed and approved by the University of Surrey Ethics Committee.

What if I have a complaint?
If you are worried about the way you have been contacted or treated during this study, you can contact:

Nan Holmes (Research Supervisor)
Department of Clinical Psychology
University of Surrey
Guildford
Surrey, GU2 7XH
Telephone: 01483 259441

What if I have a question?
If you have any questions about taking part or if you need help to complete the questionnaire please contact me, Emilie Cassell (Trainee Clinical Psychologist).

My Contact Details:
Emilie Cassell
Department of Clinical Psychology
University of Surrey
Guildford
Surrey, GU2 7XH
Tel: 01483 259441
Email: psm2ec@surrey.ac.uk

Thank you for reading this.
Hello! My name is Emilie Cassell, I am a Student Psychologist at the University of Surrey. I would like to ask your mum/dad some questions. I want to know if that's OK with you.

What are the questions about?
The questions are about what your mum/dad thinks about your social life.

Why are you asking my mum/dad to help?
I am asking your mum/dad because you have a learning disability. I am interested in what parents of young people with learning disabilities think about their child's social life. I am asking the mums/dads of all the young people at your school who have a learning disability and are between 11 and 19 to help.

Why are you asking me if it's OK for my mum/dad to help?
I am asking you if it's OK for your mum/dad to help because I will be asking them about the things you do.

Do they have to help with this research?
No. It is up to you and your mum/dad.

What should I do if I want them to help with the research?
If you want them to help, all you have to do is tell them.

What should I do if I don't want them to help with the research?
If you don't want them to help, all you have to do is tell them.
Are there any reasons why I might not want them to help with the research?
You might not want them to tell me about the things you do.

Is it good for us to take part?
It might help families like yours in the future.

Will you tell other people the things my mum/dad tells you about?
When the research is finished I will write a report. The report will talk about the things that all the parents have told me. It will not have names in it. No one will know that your mum/dad has helped me with the research.

What if I am not happy about this research?
If you are not happy about the research you can contact me and let me know.

What if I a question?
If you have a question please contact me, Emilie Cassell (Trainee Clinical Psychologist).

My address: Department of Clinical Psychology
University of Surrey
Guildford
Surrey, GU2 7XH

My telephone number: 01483 259441

My email address: psm2ec@surrey.ac.uk

Thank you for reading this.
CONSENT FORM

Parents’ views about the social well being of their child with learning disabilities.

• I, the undersigned, voluntarily agree to take part in this study.
• I have read and understood the INFORMATION SHEET provided. The aims and purpose of the study have been explained to me and I know what my participation in the study will involve.
• I understand that information about me, my family and my child will be held in the strictest confidence in accordance with the Data Protection Act (1998) and that the anonymity of those mentioned will be preserved. I understand that confidentiality will only be broken in exceptional circumstances where there are concerns about my safety, my child’s safety or the safety of others.
• I understand that I am free to withdraw from the study at any time and that I do not need to give a reason.

Where it is possible:
• My son/daughter has read the YOUNG PERSON’S INFORMATION SHEET and has indicated that he/she is happy for me to take part.

Printed name of parent/carer: ____________________________
Signature of parent/carer: ________________________________
Date: ___________________
Name of Researcher: Emilie Cassell
Signature of Researcher: ____________________________

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Appendix X: Local Support Services Sheets

**Mencap**
Mencap has family advisers service for both adults and children who have a learning disability. Some of the things they can help you with include:
- General advice and support
- Welfare benefits, housing, education and grants
- Access to voluntary and statutory services
- Advocacy and support at meetings
- You can visit them or they can visit you
Call: 0208 305 2245

**Mencap Greenlight Project**
This is an early intervention home based project supporting young people with a learning disability and their families regarding behaviour management. Call 020 8305 0321 to speak to a family adviser.

**Children’s Information Service**
The Children’s Information Service provides information on clubs, societies and leisure opportunities for young people. Call 020 8921 6921

**National Autistic Society**
The National Autistic Society has regular coffee mornings and branch meetings. They support parents, carers and people on the autistic spectrum and run swimming and drama therapy groups. Call 020 8850 3727

**Downs Syndrome Association**
The Downs Syndrome Association holds parents’ meetings and the Friday Friends Youth Club. They are also available for advice and support. Call 020 8333 7662

**Parent Partnership Officers**
Parent Partnership Officers offer an information, advice and support service for parents who have children with special educational needs. They give independent and confidential help with all aspects of SEN procedures. Call 020 8921 8433
Connexions
Connexions offer advice and support to young people between 13 and 25 years of age. Call 0800 783 7830 to speak to a personal adviser.

Toy Library
The Toy Library have a range of services including a lending library, home visiting service, youth clubs, play schemes and parent classes. Call 020 8854 7090.

Citizen Advocacy Project
Citizen Advocacy Project is an advocacy project for young people with a learning disability. Call 020 8293 3720.

School Special Education Needs Coordinator
The Special Education Needs Coordinator at your child's school or college is available to discuss any concerns you might have and advise you on appropriate support services.

Children and Adolescent Mental Health Services
This is an NHS team of professionals who specialise in serving the needs of children and adolescents. It includes doctors, nurses, social workers, psychologists, occupational therapists, art therapists, psychiatrists, family therapists, physiotherapists, speech and language therapists and more. You will need to ask your GP to refer you to this team for an appointment.
Appendix XI: Ethics

17 October 2005

Ms Emilie Cassell
Department of Psychology
School of Human Sciences

Dear Ms Cassell

Parents' views about the social-wellbeing of their child with learning disabilities
(EC/2005/90/Psych)

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for
the above research on the basis described in the submitted protocol and supporting
documentation.

Date of confirmation of ethical opinion: 17 October 2005

The list of documents reviewed and approved by the Committee is as follows:

- Document Type: Application
  Dated: 11/08/05
  Received: 19/08/05

- Document Type: Summary of Project
  Received: 19/08/05

- Document Type: Research Proposal
  Received: 19/08/05

- Document Type: Letters from Head Teachers to Parents
  Received: 19/08/05

- Document Type: Young Person's Information Sheet
  Received: 19/08/05

- Document Type: Information Sheet for Parents
  Received: 19/08/05

- Document Type: Consent Form
  Received: 19/08/05
This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected, with reasons.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
   Dr N Holmes, Supervisor, Psychology
Dear Sir/Madam,

You may remember getting an envelope like this before Christmas. If you completed the questionnaire attached and returned it, thank you and please ignore this second distribution. If you did not complete the questionnaire, I understand that you may have been away during the festive season. Now that the festivities are over, I would really appreciate it if you could take the time to complete the questionnaire.

The more I get back, the more likely it is that the project will influence the way services are provided to families like yours.

If you would like some help completing the questionnaire or would like to ask me questions I will be at the Royal Hill Campus at 10.30am on 9/11/06 and at Chariton Campus at 1.30pm on 9/11/06.

Yours Sincerely,

Emilie Cassell
23rd February 2006

Dear Parent/Carer

This is to inform you that the school has agreed for Emilie Cassell, Trainee Clinical Psychologist to contact you regarding research she is carrying out on the social wellbeing of young people with learning difficulties.

Yours sincerely

February 27th 2006

Dear Parent/Carer

School Survey

We are taking part in a survey about the social well-being of children with learning difficulties. Could you please fill in the questionnaire and return it to school or post it using the envelope enclosed.

You do not have to take part but it would be very helpful if you do.

If you need any help filling in the questions please contact school.

Many thanks

Yours faithfully
Dear Parents/Carers,

We have been contacted by a research student, Emilie Cassell, from the University of Surrey.

She has asked for permission to contact families in the school for research on parents’ views regarding the well being of children with Statements of Special Educational Needs.

The school has talked to Emilie and we believe the results of such research may benefit our children and those following in the coming years.

The information and questionnaires regarding the research are enclosed with this letter. Participation in this research is on a purely voluntary basis.

Yours sincerely
27 January 2006

Ms Emilie Cassell
Trainee Clinical Psychologist
Department of Psychology

Dear Ms Cassell

Parent's views about the social-wellbeing of their child with learning disabilities (EC/2005/90/PSYCH) - AMENDMENT

I am writing to inform you that the Chairman, on behalf of the Ethics Committee, has considered the Amendments requested to the above protocol and has approved them on the understanding that the Ethical Guidelines for Teaching and Research are observed and the following condition is met:

• That you obtain written permission from the Head Teachers of the three additional schools you propose to include in your research, and forward a copy of these to me to be placed on the Committee's records.

Date of confirmation of ethical opinion: 17 October 2005
Date of approval of amendment to protocol: 27 January 2006

The list of amended documents reviewed and approved by the Chairman is as follows:

Document Type: Your Letter Requesting Amendments
Dated: 18/01/06
Received: 23/01/06

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
Dr N Holmes, Supervisor, Psychology
Dear Sir/Madam,

Early last year a study was conducted in 5 special needs schools and 1 integrated college in South East London. It was about the social well-being of young people (11 to 19) with learning disabilities. The results of this study showed that:

- On average parents felt social well-being was “very important” for their child with learning disabilities’ current and future well-being
- 71% of young people with learning disabilities have one or more friends
- 41% of young people with learning disabilities carry out recreational activities with friends a few times a year
- 81% of young people with learning disabilities carry out recreational activities with their families a few times a year
- Young people with learning disabilities who were reported to have behavioural problems, mobility problems or to be in need of constant attention were less likely to have friends
- Young people who were more severely learning disabled were less likely to have friends
- Obstacles to young people with learning disabilities’ social lives included practical issues such as transport or travel distances and the general public’s attitude

We would like to know if this represents other people’s experiences.

If you would like to help us with this, please answer the questions on the next sheet and return this sheet in the FREEPOST envelope provided. Your responses are anonymous and will contribute to the final report on the study.

If you would like to discuss these issues further please include your telephone number and a convenient time for me to call you in the space provided on the next sheet.
Please circle the answer that best represents your views for each of the following questions:

Do the results fit with your personal experience?  yes/no

Do you think the results reflect how things are generally?  yes/no

Did you complete a questionnaire on the social well-being of your child with learning disabilities?  yes/no

Please return this sheet in the FREEPOST envelope provided.

Thank you for your contribution.

Emilie Cassell
Trainee Clinical Psychologist
University of Surrey
Appendix XVI: Ethics III

15 November 2006

Ms Emilie Cassell
Department of Psychology
School of Human Sciences

Dear Ms Cassell

Parents' views about the social-wellbeing of their child with learning disabilities [EC/2005/90/Psych] - AMENDMENT

I am writing to inform you that the Chairman, on behalf of the Ethics Committee, has considered the Amendments requested to the above protocol and has approved them on the understanding that the Ethical Guidelines for Teaching and Research are observed.

Date of confirmation of ethical opinion: 17 October 2005
Date of approval of amendment to protocol: 15 November 2006

The list of amended documents reviewed and approved by the Chairman is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow up Letter to Parents</td>
<td>09/11/2006</td>
</tr>
</tbody>
</table>

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
Dr N Holmes, Supervisor, Psychology
## Appendix XVII: Independent Analysis

### Table 1: Content of responses to question 19 and 20 that referred to further obstacles to children's social lives

<table>
<thead>
<tr>
<th>N</th>
<th>Themes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>11 (22%)*</td>
<td>Child's communication difficulties</td>
<td>&quot;...lack of verbal communication is the largest obstacle to my sons' progression and development...”; &quot;...without speech... it can be difficult to socialise...”; &quot;...No knowledge of what to do when lost...&quot;</td>
</tr>
<tr>
<td>6 (12%)*</td>
<td>Child's poor social skills/immaturity</td>
<td>&quot;...without ... an understanding of social interaction... it can be difficult to socialise...”; &quot;...lacking social skills...”; &quot;For Sophie to get on with people...&quot;</td>
</tr>
<tr>
<td>6 (12%)*</td>
<td>Child's behaviour problems</td>
<td>&quot;...swears a lot...”, &quot;...can be difficult to discipline and control...”; &quot;...major fear of dogs, birds, cats...&quot;</td>
</tr>
<tr>
<td>6 (12%)*</td>
<td>Public attitude to people with disabilities</td>
<td>&quot;...the general public need to be aware that there are people of different abilities in the community...”; &quot;...None of the children who live down our road want anything to do with my child because he is 'different'.”</td>
</tr>
<tr>
<td>6 (12%)*</td>
<td>Transport Issues</td>
<td>&quot;...my child would like to go to after school club but they won’t provide transport...since we don’t drive and have a two year old this is impossible...; &quot;...The only obstacle is that he can’t make his own way to places...&quot;</td>
</tr>
<tr>
<td>5 (10%)*</td>
<td>Living a long way from school or school taking children from a large area</td>
<td>&quot;...he lives a long way from school and doesn’t see his school friends outside of school...”; &quot;...because his friends from school live far away...he hasn’t got any friends...”; &quot;...the fact that her school takes children from a large area means she has no school friends that are close to our home, whom she could socialise with after school.”</td>
</tr>
<tr>
<td>3 (6%)*</td>
<td>Lack of confidence</td>
<td>&quot;...is very nervous of taking bus alone...”; &quot;...my son lacks much confidence and needs a lot of encouragement. He lacks confidence in trying to do things for himself and going out alone...”</td>
</tr>
<tr>
<td>3 (6%)*</td>
<td>A dislike for social activities</td>
<td>&quot;... would really rather be left alone...”; &quot;... does not like going to clubs...”; &quot;...is always on his own...”</td>
</tr>
<tr>
<td>2 (4%)*</td>
<td>Lack of support for carers</td>
<td>&quot;...lack of carers for respite...”; &quot;...[the] school continually badger her father but offer no help themselves. He is 67 years old and ...needs to be given help”; &quot;...I’m a single parent...”</td>
</tr>
<tr>
<td>3 (6%)*</td>
<td>Other people for carers to care for</td>
<td>&quot;...with 3 children...”; &quot;...we have a two year old...”; &quot;...having 3 other children...”</td>
</tr>
<tr>
<td>3 (6%)*</td>
<td>Child’s poor daily living/self care skills</td>
<td>&quot;...no knowledge of money...”; &quot;...Without [...] an understanding of social interaction”</td>
</tr>
<tr>
<td>2 (4%)*</td>
<td>Lack of clubs for children</td>
<td>&quot;...lack of clubs etc. for children with learning disabilities...”; &quot;...no sports clubs or clubs...for kids with or without special needs”</td>
</tr>
<tr>
<td>1 (2%)*</td>
<td>Sensory difficulties</td>
<td>&quot;Doesn’t like loud noises.”</td>
</tr>
<tr>
<td>N</td>
<td>Themes</td>
<td>Quotes</td>
</tr>
<tr>
<td>----</td>
<td>------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1</td>
<td>Carer’s working hours</td>
<td>“Transport to get her there and back if I am working.”</td>
</tr>
<tr>
<td>1</td>
<td>Carer’s own issues</td>
<td>“Feeling confident about leaving home to go to work if they have a day off without feeling irresponsible.”</td>
</tr>
<tr>
<td>1</td>
<td>Child’s mobility problems</td>
<td>“...i.e. wheelchairs, white canes...”</td>
</tr>
<tr>
<td>1</td>
<td>Carer’s lack of information/knowledge about social activities</td>
<td>“...not sure what else to do...”</td>
</tr>
<tr>
<td>1</td>
<td>Child’s vulnerability</td>
<td>“...level of vulnerability...”</td>
</tr>
</tbody>
</table>

Table 2: Content of responses to question 19 and 20 that referred to service development for the promotion of children’s social lives

<table>
<thead>
<tr>
<th>N</th>
<th>Themes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 (18%)*</td>
<td>More after school clubs for children with special needs</td>
<td>“…more clubs for SE...”; “...I would like to see more groups for children with special needs...”; “I would like more clubs/facilities open to children with SEN rather than always having separate groups for them as I think it is important for them to mix with all types of people.”</td>
</tr>
<tr>
<td>5 (10%)*</td>
<td>More transport/free transport</td>
<td>“…transport to and from clubs...”; “...activities ...with transport pick up/drop off...”; “...free travel pass for the family so they could go out a lot more...”; “...by at least providing a freedom pass as she only uses public transport to get somewhere...”</td>
</tr>
<tr>
<td>5 (10%)*</td>
<td>After school clubs for children of mixed abilities</td>
<td>“…more...‘normal’ clubs not just catering for those with special needs...”; “...more gatherings or meetings where they can socialise and interact with a wide range of people...”</td>
</tr>
<tr>
<td>5 (10%)*</td>
<td>One-to-one support for young person</td>
<td>“…counselling...”; “…son-rise programme...”; “I would like help to know where she could go to places to help her speech improve...”</td>
</tr>
<tr>
<td>4 (8%)*</td>
<td>More weekend/holiday clubs for children with special needs</td>
<td>“…more summer holiday schemes...”; “…maybe schools/colleges organising social events some weekends and holidays...”; “...more activities: ...at weekends.”</td>
</tr>
<tr>
<td>4 (8%)*</td>
<td>More educational classes for children with special needs</td>
<td>“…self defence or yoga for people with special needs...”; “...drama group...”; “…sports clubs...”</td>
</tr>
</tbody>
</table>
## Table 3: Miscellaneous answers

<table>
<thead>
<tr>
<th>N</th>
<th>Themes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>Miscellaneous</td>
<td>“X is having a difficult year with all sorts of problems..”; “secure help”; “she is always on her own”</td>
</tr>
</tbody>
</table>
## Appendix XVIII: Skewness and Kurtosis

Table 1: Skewness and Kurtosis of non-normally distributed variables

<table>
<thead>
<tr>
<th>Variables</th>
<th>Skewness</th>
<th>Standard Error</th>
<th>Kurtosis</th>
<th>Standard Error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents' choice of severity descriptor</td>
<td>-0.89</td>
<td>0.28</td>
<td>0.97</td>
<td>0.56</td>
</tr>
<tr>
<td>Choice of severity descriptor in ESN</td>
<td>-0.1</td>
<td>0.29</td>
<td>-0.12</td>
<td>0.58</td>
</tr>
<tr>
<td>Friend network size</td>
<td>1.73</td>
<td>0.28</td>
<td>2.67</td>
<td>0.56</td>
</tr>
<tr>
<td>Network quality</td>
<td>-0.17</td>
<td>0.34</td>
<td>0.08</td>
<td>0.66</td>
</tr>
<tr>
<td>Frequency of contact with friends</td>
<td>-0.11</td>
<td>0.36</td>
<td>-0.4</td>
<td>0.71</td>
</tr>
<tr>
<td>Number of activities alone</td>
<td>2.99</td>
<td>0.28</td>
<td>11.37</td>
<td>0.55</td>
</tr>
<tr>
<td>Frequency of activities alone</td>
<td>2.22</td>
<td>0.28</td>
<td>5.1</td>
<td>0.56</td>
</tr>
<tr>
<td>Resource availability</td>
<td>-1.29</td>
<td>0.28</td>
<td>1.14</td>
<td>0.55</td>
</tr>
<tr>
<td>Independent use</td>
<td>1.24</td>
<td>0.28</td>
<td>0.69</td>
<td>0.55</td>
</tr>
</tbody>
</table>
Appendix XIX: Prevalence Information
These figures represent the prevalence of pupils' primary learning difficulties. Thirty-five pupils also had secondary learning difficulties.

<table>
<thead>
<tr>
<th>Type of Difficulty</th>
<th>Profound</th>
<th>Severe</th>
<th>Moderate</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>36</td>
<td>1</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Auditory Impairment</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Language Impairment</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Speech and Language</td>
<td>17</td>
<td>13</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Behavioral Difficulties</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Social Difficulties</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Emotional Difficulties</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mental Health Difficulties</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Spectrum Disorder</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>General Outcome</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Autism</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>36</td>
<td>1</td>
<td>2</td>
<td>18</td>
</tr>
</tbody>
</table>

Table 1: Prevalence and severity of specific learning and physical disabilities among pupils at the IS.
| Attention deficit, language difficulties, mathematical problems and social difficulties, sensory impairments, |
| number of pupils with emotional, behavioural and special educational needs. |
| Most pupils have moderate learning difficulties. |
| 2005 | Special Needs School 1 |
| Also have language difficulties, a small number of pupils with severe emotional, behavioural and special educational needs. |
| Most pupils have moderate learning difficulties. |
| 2006 | Special Needs School 2 |
| Emotional, behavioural and special educational needs. There is a small but increasing number of pupils with severe emotional, behavioural and special educational needs. |
| Most pupils have moderate learning difficulties. |
| 2002 | Special Needs School 3 |
| Multiple learning difficulties, some have multiple special educational needs. |
| Most pupils have severe or profound and multiple disabilities. |
| 2002 | Special Needs School 4 |

Table 2: Extracts from Special Needs School’s O1sted Reports Regarding Nature and Severity of Difficulties among Pupils.
<table>
<thead>
<tr>
<th>#</th>
<th>Number of people from sample</th>
<th>Percentage of all disorders</th>
<th>309</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>914</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>202</td>
<td>Central Nervous System disorders</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>146</td>
<td>Mental Handicap</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>47</td>
<td>Global Developmental Delay</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>14</td>
<td>Epilepsy</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>22</td>
<td>Down Syndrome</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>300</td>
<td>Depression</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>760</td>
<td>Cerebral Palsy</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>2408</td>
<td>Autism Spectrum Disorders and Behavioral Disorders</td>
<td>309</td>
</tr>
</tbody>
</table>

*This table includes children with medical conditions such as cancer that are not shown here.*
Appendix XX: Resource Use

Figure 1: Accessibility of each resource across sample
Figure 2: Availability of each resource across sample
Figure 3: Independent use of each resource across sample
Figure 4: Aided use of each resource across sample
<table>
<thead>
<tr>
<th>Resources</th>
<th>N*</th>
<th>Never</th>
<th>A few times a year</th>
<th>About once a month</th>
<th>A few times a month</th>
<th>A few times a week</th>
<th>About once a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Makes phone calls</td>
<td>70</td>
<td>21</td>
<td>13</td>
<td>1</td>
<td>7</td>
<td>16</td>
<td>12</td>
</tr>
<tr>
<td>Sends text messages</td>
<td>65</td>
<td>35</td>
<td>5</td>
<td>2</td>
<td>8</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Sends emails</td>
<td>48</td>
<td>33</td>
<td>6</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Accesses internet chat room</td>
<td>50</td>
<td>42</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Uses msn</td>
<td>52</td>
<td>39</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Uses public transport</td>
<td>65</td>
<td>13</td>
<td>22</td>
<td>2</td>
<td>14</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Uses private transport</td>
<td>63</td>
<td>11</td>
<td>6</td>
<td>1</td>
<td>7</td>
<td>16</td>
<td>22</td>
</tr>
<tr>
<td>Sends letters/cards</td>
<td>63</td>
<td>23</td>
<td>35</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

* Low sample numbers reflect resource unavailability as well as missing data
### Appendix XXI: Indicator Importance Ratings

#### Table 1: Importance ratings given to indicators of quality of life domains

<table>
<thead>
<tr>
<th>Scale items</th>
<th>N*</th>
<th>Doesn’t apply Rating: 0</th>
<th>Of no importance Rating: 1</th>
<th>Of little importance Rating: 2</th>
<th>Important Rating: 3</th>
<th>Very important Rating: 4</th>
<th>Extremely important Rating: 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling safe</td>
<td>72</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>16</td>
<td>50</td>
</tr>
<tr>
<td>Having close personal relationships</td>
<td>71</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>13</td>
<td>25</td>
<td>30</td>
</tr>
<tr>
<td>Being independent</td>
<td>72</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td>24</td>
<td>39</td>
</tr>
<tr>
<td>Being accepted</td>
<td>73</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>7</td>
<td>21</td>
<td>42</td>
</tr>
<tr>
<td>Having privacy</td>
<td>72</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>21</td>
<td>14</td>
<td>34</td>
</tr>
<tr>
<td>Having enough money</td>
<td>72</td>
<td>1</td>
<td>4</td>
<td>4</td>
<td>19</td>
<td>17</td>
<td>27</td>
</tr>
<tr>
<td>Being in good health</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>8</td>
<td>14</td>
<td>49</td>
</tr>
<tr>
<td>Being happy</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>18</td>
<td>52</td>
</tr>
<tr>
<td>Having choices</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>12</td>
<td>21</td>
<td>37</td>
</tr>
<tr>
<td>Having support from friends and family</td>
<td>72</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>21</td>
<td>49</td>
</tr>
<tr>
<td>Access to leisure activities</td>
<td>72</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>19</td>
<td>26</td>
<td>26</td>
</tr>
<tr>
<td>Access to education</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>23</td>
<td>44</td>
</tr>
<tr>
<td>Being free from stress</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>12</td>
<td>17</td>
<td>43</td>
</tr>
<tr>
<td>Having valued role</td>
<td>71</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>17</td>
<td>22</td>
<td>29</td>
</tr>
<tr>
<td>Having friends</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>8</td>
<td>21</td>
<td>43</td>
</tr>
<tr>
<td>Owning own home</td>
<td>71</td>
<td>4</td>
<td>6</td>
<td>26</td>
<td>19</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Having personal goals</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>18</td>
<td>23</td>
<td>27</td>
</tr>
<tr>
<td>Right to vote</td>
<td>72</td>
<td>6</td>
<td>8</td>
<td>11</td>
<td>23</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>Scale items</td>
<td>N*</td>
<td>Doesn’t apply Rating: 0</td>
<td>Of no importance Rating: 1</td>
<td>Of little importance Rating: 2</td>
<td>Important Rating: 3</td>
<td>Very important Rating: 4</td>
<td>Extremely important Rating: 5</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>----</td>
<td>-------------------------</td>
<td>-----------------------------</td>
<td>---------------------------------</td>
<td>---------------------</td>
<td>---------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Having skills</td>
<td>72</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>12</td>
<td>19</td>
<td>39</td>
</tr>
<tr>
<td>Being mobile</td>
<td>70</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>11</td>
<td>18</td>
<td>36</td>
</tr>
<tr>
<td>Religion</td>
<td>72</td>
<td>9</td>
<td>16</td>
<td>22</td>
<td>13</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Living in local community</td>
<td>72</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>18</td>
<td>22</td>
<td>27</td>
</tr>
<tr>
<td>Being employed</td>
<td>71</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>9</td>
<td>25</td>
<td>29</td>
</tr>
<tr>
<td>Having social interactions</td>
<td>72</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>10</td>
<td>27</td>
<td>32</td>
</tr>
<tr>
<td>Having health diet</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>12</td>
<td>23</td>
<td>36</td>
</tr>
<tr>
<td>Having possessions</td>
<td>70</td>
<td>2</td>
<td>1</td>
<td>14</td>
<td>19</td>
<td>13</td>
<td>21</td>
</tr>
<tr>
<td>Being respected</td>
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<td>0</td>
<td>0</td>
<td>10</td>
<td>22</td>
<td>40</td>
</tr>
<tr>
<td>Being competent</td>
<td>71</td>
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<td>0</td>
<td>1</td>
<td>13</td>
<td>21</td>
<td>36</td>
</tr>
<tr>
<td>Access to information on rights</td>
<td>71</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>23</td>
<td>13</td>
<td>27</td>
</tr>
<tr>
<td>Having meaningful things to do</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>17</td>
<td>20</td>
<td>35</td>
</tr>
</tbody>
</table>

*Varying sample sizes reflect numbers of parents for whom items didn’t apply as well as missing data.
### Appendix XXII: Child Characteristic Impact Ratings

#### Table 1: Distributions of impact ratings for each child characteristic

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N*</th>
<th>Not at all Rating:1</th>
<th>A little Rating:2</th>
<th>Somewhat Rating:3</th>
<th>Quite a lot Rating:4</th>
<th>Very much Rating:5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing problems</td>
<td>39</td>
<td>16</td>
<td>5</td>
<td>6</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Incontinence</td>
<td>33</td>
<td>15</td>
<td>8</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Property destruction</td>
<td>50</td>
<td>12</td>
<td>13</td>
<td>10</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Mobility problems</td>
<td>45</td>
<td>15</td>
<td>8</td>
<td>13</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Inappropriate personal habits</td>
<td>56</td>
<td>17</td>
<td>7</td>
<td>15</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>Self injury</td>
<td>43</td>
<td>21</td>
<td>9</td>
<td>6</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Problems speaking</td>
<td>66</td>
<td>8</td>
<td>13</td>
<td>16</td>
<td>10</td>
<td>19</td>
</tr>
<tr>
<td>Visual difficulties</td>
<td>44</td>
<td>26</td>
<td>4</td>
<td>9</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Physical aggression towards others</td>
<td>59</td>
<td>11</td>
<td>20</td>
<td>17</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Problems understanding what is said</td>
<td>70</td>
<td>3</td>
<td>13</td>
<td>22</td>
<td>15</td>
<td>17</td>
</tr>
<tr>
<td>Disturbing noises</td>
<td>58</td>
<td>13</td>
<td>10</td>
<td>15</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>Temper tantrums</td>
<td>65</td>
<td>9</td>
<td>26</td>
<td>14</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Requires constant attention</td>
<td>64</td>
<td>7</td>
<td>13</td>
<td>14</td>
<td>14</td>
<td>16</td>
</tr>
<tr>
<td>Anti-social behaviour</td>
<td>55</td>
<td>16</td>
<td>14</td>
<td>12</td>
<td>9</td>
<td>4</td>
</tr>
</tbody>
</table>

*Varying sample sizes reflect numbers of parents that indicated that a characteristic ‘did not apply’ as well as missing data.*
Appendix XXIII: Parental Circumstances Impact Ratings

Table 1: Distribution of impact ratings for each parental circumstance

<table>
<thead>
<tr>
<th>Factors</th>
<th>N*</th>
<th>Not at all Rating: 1</th>
<th>A little Rating: 2</th>
<th>Somewhat Rating: 3</th>
<th>Quite a lot Rating: 4</th>
<th>Very much Rating: 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Income</td>
<td>59</td>
<td>13</td>
<td>17</td>
<td>11</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Working Hours</td>
<td>51</td>
<td>5</td>
<td>8</td>
<td>17</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>Caring for other children</td>
<td>51</td>
<td>5</td>
<td>10</td>
<td>13</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td>Caring for other children with disabilities/health issues</td>
<td>26</td>
<td>10</td>
<td>0</td>
<td>5</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Caring for adults with disabilities/health issues</td>
<td>20</td>
<td>8</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Own physical health issues</td>
<td>50</td>
<td>19</td>
<td>15</td>
<td>6</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Own emotional issues</td>
<td>57</td>
<td>17</td>
<td>16</td>
<td>14</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

*Varying sample numbers reflect numbers of parents for whom factors did not apply as well as missing data.
### Table 1: One-tailed Pearson’s and Spearman’s correlations between measures of SWB and measures of parental support to use resources to make and maintain friendships

<table>
<thead>
<tr>
<th>Variables</th>
<th>Number of factors</th>
<th>Quality of network</th>
<th>Frequency of contacts with friends</th>
<th>Number of activities carried out with friends</th>
<th>Frequency of activities carried out with friends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of aided resource activities</td>
<td>r = -0.026 (p = 0.41) n = 71</td>
<td>r = 0.086 (p = 0.28) n = 50</td>
<td>r = -0.017 (p = 0.46) n = 43</td>
<td>r = 0.22* (p&lt;0.05) n = 73</td>
<td>r = 0.073 (p = 0.27) n = 72</td>
</tr>
<tr>
<td>Frequency of aided resource activities</td>
<td>r = 0.092 (p = 0.24) n = 59</td>
<td>r = -0.021 (p = 0.45) n = 42</td>
<td>r = -0.018 (p = 0.46) n = 38</td>
<td>r = 0.28* (p&lt;0.05) n = 60</td>
<td>r = 0.28* (p&lt;0.05) n = 60</td>
</tr>
<tr>
<td>Resource accessibility</td>
<td>r = 0.067 (p = 0.29) n = 71</td>
<td>r = 0.144 (p = 0.16) n = 50</td>
<td>r = 0.145 (p = 0.18) n = 43</td>
<td>r = 0.33** (p&lt;0.01) n = 73</td>
<td>r = 0.25* (p&lt;0.05) n = 72</td>
</tr>
</tbody>
</table>

*Significant at the 0.05 level
** Significant at the 0.01 level
Appendix XXV: Results for Question 2

Table 1: One-tailed Pearson’s correlations between measures of importance of SWB and measures of parental support to use resources to make and maintain relationships

<table>
<thead>
<tr>
<th>Importance of SWB</th>
<th>Number of resources actually used with help</th>
<th>Mean frequency of aided resource use</th>
<th>Resource accessibility</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( r = -0.01 ) (( p = 0.48 )) ( n = 72 )</td>
<td>( r = -0.09 ) (( p = 0.24 )) ( n = 60 )</td>
<td>( r = 0.193 ) (( p = 0.05 )) ( n = 72 )</td>
</tr>
</tbody>
</table>
### Table 1: One-tailed Spearman’s correlations between measures of severity of disability and measures of parental support to use resources to make and maintain relationships

<table>
<thead>
<tr>
<th></th>
<th>Number of aided resources activities</th>
<th>Frequency of aided resource use</th>
<th>Resource accessibility</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Severity on SEN</strong></td>
<td>$r = 0.15$</td>
<td>$r = 0.03$</td>
<td>$r = 0.05$</td>
</tr>
<tr>
<td></td>
<td>($p = 0.11$)</td>
<td>($p = 0.41$)</td>
<td>($p = 0.34$)</td>
</tr>
<tr>
<td></td>
<td>$n = 66$</td>
<td>$n = 55$</td>
<td>$n = 66$</td>
</tr>
<tr>
<td><strong>Severity by parents</strong></td>
<td>$r = -0.035$</td>
<td>$r = 0.015$</td>
<td>$r = -0.136$</td>
</tr>
<tr>
<td></td>
<td>($p = 0.39$)</td>
<td>($p = 0.46$)</td>
<td>($p = 0.13$)</td>
</tr>
<tr>
<td></td>
<td>$n = 72$</td>
<td>$n = 60$</td>
<td>$n = 72$</td>
</tr>
</tbody>
</table>
## Table 1: One-tailed Pearson’s and Spearman’s correlations between measures of the impact of child characteristics and measures of parental support to use resources to make and maintain relationships

<table>
<thead>
<tr>
<th>Variables</th>
<th>Number of aided resource activities</th>
<th>Frequency of aided resource use</th>
<th>Resource accessibility</th>
</tr>
</thead>
</table>
| Overall impact of child characteristics | $r = -0.07$  
( $p = 0.29$)  
n = 72 | $r = 0.05$  
( $p = 0.35$)  
n = 60 | $r = -0.18$  
( $p = 0.07$)  
n = 72 |
| Hearing impairment               | $r = -0.07$  
( $p = 0.33$)  
n = 39 | $r = 0.26$  
( $p = 0.12$)  
n = 22 | $r = -0.03$  
( $p = 0.43$)  
n = 39 |
| Incontinence                     | $r = 0.03$  
( $p = 0.44$)  
n = 33 | $r = 0.03$  
( $p = 0.44$)  
n = 28 | $r = -0.03$  
( $p = 0.43$)  
n = 33 |
| Property destruction             | $r = -0.1$  
( $p = 0.24$)  
n = 50 | $r = 0.17$  
( $p = 0.15$)  
n = 41 | $r = -0.27*$  
( $p < 0.05$)  
n = 50 |
| Mobility problems                | $r = 0.14$  
( $p = 0.18$)  
n = 45 | $r = 0.05$  
( $p = 0.37$)  
n = 38 | $r = -0.06$  
( $p = 0.35$)  
n = 45 |
| Inappropriate personal habits     | $r = -0.23$  
( $p < 0.05$)  
n = 56 | $r = 0.05$  
( $p = 0.36$)  
n = 47 | $r = -0.21$  
( $p = 0.06$)  
n = 56 |
| Self Injury                      | $r = -0.31*$  
( $p < 0.05$)  
n = 43 | $r = 0.05$  
( $p = 0.39$)  
n = 36 | $r = -0.36**$  
( $p < 0.01$)  
n = 43 |
| Problems speaking                | $r = -0.02$  
( $p = 0.43$)  
n = 66 | $r = 0.06$  
( $p = 0.32$)  
n = 56 | $r = -0.25*$  
( $p < 0.05$)  
n = 66 |
| Visual impairment                | $r = -0.07$  
( $p = 0.32$)  
n = 44 | $r = 0.14$  
( $p = 0.19$)  
n = 39 | $r = -0.1$  
( $p = 0.27$)  
n = 44 |
| Physical aggression              | $r = -0.02$  
( $p = 0.43$)  
n = 59 | $r = 0.1$  
( $p = 0.24$)  
n = 48 | $r = -0.02$  
( $p = 0.44$)  
n = 59 |
| Problems understanding           | $r = 0.06$  
( $p = 0.3$)  
n = 70 | $r = 0.04$  
( $p = 0.37$)  
n = 58 | $r = -0.01$  
( $p = 0.47$)  
n = 70 |
| Makes disturbing noises           | $r = -0.001$  
( $p = 0.5$)  
n = 58 | $r = -0.11$  
( $p = 0.23$)  
n = 48 | $r = -0.19$  
( $p = 0.07$)  
n = 58 |
| Temper tantrums                  | $r = -0.06$  
( $p = 0.31$)  
n = 65 | $r = -0.03$  
( $p = 0.41$)  
n = 54 | $r = 0.05$  
( $p = 0.34$)  
n = 65 |
| In need of constant attention    | $r = -0.03$  
( $p = 0.42$)  
n = 64 | $r = 0.03$  
( $p = 0.4$)  
n = 55 | $r = -0.15$  
( $p = 0.11$)  
n = 64 |
| Anti-social behaviour            | $r = -0.14$  
( $p = 0.14$)  
n = 55 | $r = 0.05$  
( $p = 0.36$)  
n = 46 | $r = -0.08$  
( $p = 0.27$)  
n = 55 |
Appendix XXVIII: Results for Question 5

Table 1: Pearson's and Spearmans' correlations between measures of the impact of parental circumstances and measures of parental support to use resources to make and maintain relationships

<table>
<thead>
<tr>
<th>Measure</th>
<th>Number of aided resource activities</th>
<th>Frequency of aided resource use</th>
<th>Resource accessibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall impact of parental circumstances</td>
<td>$r = 0.03$  ($p = 0.39$)</td>
<td>$r = 0.07$  ($p = 0.31$)</td>
<td>$r = -0.08$ ($p = 0.24$)</td>
</tr>
<tr>
<td></td>
<td>$n = 69$</td>
<td>$n = 59$</td>
<td>$n = 69$</td>
</tr>
<tr>
<td>Family income</td>
<td>$r = -0.09$  ($p = 0.24$)</td>
<td>$r = -0.19$  ($p = 0.09$)</td>
<td>$r = -0.11$ ($p = 0.2$)</td>
</tr>
<tr>
<td></td>
<td>$n = 59$</td>
<td>$n = 53$</td>
<td>$n = 59$</td>
</tr>
<tr>
<td>Working hours</td>
<td>$r = -0.19$  ($p = 0.09$)</td>
<td>$r = -0.12$  ($p = 0.2$)</td>
<td>$r = -0.2$ ($p = 0.08$)</td>
</tr>
<tr>
<td></td>
<td>$n = 51$</td>
<td>$n = 47$</td>
<td>$n = 51$</td>
</tr>
<tr>
<td>Caring for other children</td>
<td>$r = -0.12$  ($p = 0.19$)</td>
<td>$r = -0.13$  ($p = 0.2$)</td>
<td>$r = -0.5$ ($p = 0.14$)</td>
</tr>
<tr>
<td></td>
<td>$n = 51$</td>
<td>$n = 43$</td>
<td>$n = 51$</td>
</tr>
<tr>
<td>Caring for other disabled children</td>
<td>$r = 0.36^*$  ($p &lt; 0.05$)</td>
<td>$r = 0.3$  ($p = 0.09$)</td>
<td>$r = 0.28$ ($p = 0.8$)</td>
</tr>
<tr>
<td></td>
<td>$n = 26$</td>
<td>$n = 22$</td>
<td>$n = 26$</td>
</tr>
<tr>
<td>Caring for adults</td>
<td>$r = 0.51^*$  ($p &lt; 0.05$)</td>
<td>$r = 0.05$  ($p = 0.43$)</td>
<td>$r = 0.34$ ($p = 0.07$)</td>
</tr>
<tr>
<td></td>
<td>$n = 20$</td>
<td>$n = 17$</td>
<td>$n = 20$</td>
</tr>
<tr>
<td>Own physical problems</td>
<td>$r = -0.02$  ($p = 0.45$)</td>
<td>$r = 0.26^*$  ($p &lt; 0.05$)</td>
<td>$r = -0.01$ ($p = 0.48$)</td>
</tr>
<tr>
<td></td>
<td>$n = 50$</td>
<td>$n = 41$</td>
<td>$n = 50$</td>
</tr>
<tr>
<td>Own emotional problems</td>
<td>$r = -0.06$  ($p = 0.32$)</td>
<td>$r = 0.16$  ($p = 0.13$)</td>
<td>$r = 0.06$ ($p = 0.31$)</td>
</tr>
<tr>
<td></td>
<td>$n = 57$</td>
<td>$n = 49$</td>
<td>$n = 57$</td>
</tr>
</tbody>
</table>

Table 2: Independent samples t-tests for differences between parents who receive support and those who do not on measures of the support they give their child to use resources to make and maintain relationships

<table>
<thead>
<tr>
<th>Measure</th>
<th>t</th>
<th>df</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource accessibility</td>
<td>0.13</td>
<td>70</td>
<td>0.89</td>
</tr>
<tr>
<td>Frequency of aided resource use</td>
<td>0.31</td>
<td>58</td>
<td>0.76</td>
</tr>
<tr>
<td>Number of aided resource activities</td>
<td>-1.84</td>
<td>70</td>
<td>0.07</td>
</tr>
</tbody>
</table>
Appendix XXIX: Results for Question 7

Table 1: Two-tailed partial correlations between measures of the support parents give their child to use resources and measures of children’s levels of recreational activity, controlling for other variables

<table>
<thead>
<tr>
<th>Controlled Variables</th>
<th>No of activities with friends</th>
<th>No of activities with friends Vs Frequency of aided resource activities</th>
<th>No of activities with friends Vs Resource accessibility</th>
<th>Frequency of activities carried out with friends Vs Resource accessibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Importance of SWB</td>
<td>r = 0.2 (p = 0.08) n = 69</td>
<td>r = 0.28* (p&lt;0.05) n = 57</td>
<td>r = 0.32** (p&lt;0.01) n = 69</td>
<td>r = 0.28* (p&lt;0.05) n = 57</td>
</tr>
<tr>
<td>Child characteristics</td>
<td>r = 0.24* (p&lt;0.05) n = 69</td>
<td>r = 0.29* (p&lt;0.05) n = 57</td>
<td>r = 0.3* (p&lt;0.05) n = 69</td>
<td>r = 0.28* (p&lt;0.05) n = 57</td>
</tr>
<tr>
<td>Parental circumstances</td>
<td>r = 0.26* (p&lt;0.05) n = 66</td>
<td>r = 0.29* (p&lt;0.05) n = 56</td>
<td>r = 0.3* (p&lt;0.05) n = 66</td>
<td>r = 0.29* (p&lt;0.05) n = 56</td>
</tr>
</tbody>
</table>

*Significant at the 0.05 level
** Significant at the 0.01 level
Table 2: Two-tailed partial correlations between measures of the support parents give their child to use resources and measures of the impact of parental circumstances, controlling for other variables

<table>
<thead>
<tr>
<th>Controlled variables</th>
<th>Number of aided resource activities Vs Caring for other disabled children</th>
<th>Number of unaided resource activities Vs Caring for adults</th>
<th>Frequency of independent resource use Vs Caring for other disabled children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of activities with friends</td>
<td>( r = 0.39^* ) ( (p = 0.05) ) ( n = 23 )</td>
<td>( r = 0.61^* ) ( (p&lt;0.01) ) ( n = 17 )</td>
<td>( r = 0.54^* ) ( (p&lt;0.05) ) ( n = 13 )</td>
</tr>
<tr>
<td>Frequency of activities with friends</td>
<td>( r = 0.4^* ) ( (p = 0.05) ) ( n = 22 )</td>
<td>( r = 0.55^* ) ( (p&lt;0.05) ) ( n = 17 )</td>
<td>( r = 0.51 ) ( (p = 0.06) ) ( n = 12 )</td>
</tr>
<tr>
<td>Importance of SWB</td>
<td>( r = 0.44^* ) ( (p&lt;0.05) ) ( n = 22 )</td>
<td>( r = 0.54^* ) ( (p&lt;0.05) ) ( n = 17 )</td>
<td>( r = 0.46 ) ( (p = 0.09) ) ( n = 12 )</td>
</tr>
<tr>
<td>Overall impact of child characteristics</td>
<td>( r = 0.33 ) ( (p = 0.1) ) ( n = 23 )</td>
<td>( r = 0.45 ) ( (p = 0.05) ) ( n = 17 )</td>
<td>( r = 0.47 ) ( (p = 0.07) ) ( n = 13 )</td>
</tr>
</tbody>
</table>

\( ^* \) Significant at the 0.05 level
\( ^{**} \) Significant at the 0.01 level
## Appendix XXX: Qualitative Themes

### Table 1: Content of responses to question 19 and 20 that referred to further obstacles to children's social lives

<table>
<thead>
<tr>
<th>N</th>
<th>Themes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 (18%)</td>
<td>Child's communication difficulties</td>
<td>&quot;...lack of verbal communication is the largest obstacle to my sons' progression and development...&quot;; &quot;...without speech... it can be difficult to socialise...&quot;; &quot;...she cannot have a dialogue... that hinders her from making friends...&quot;</td>
</tr>
<tr>
<td>8 (16%)</td>
<td>Child's poor social skills/immaturity</td>
<td>&quot;...without... an understanding of social interaction... it can be difficult to socialise...&quot;; &quot;...lacking social skills...&quot;; &quot;He finds it difficult to make friends his own age because he is not as mature...&quot;</td>
</tr>
<tr>
<td>7 (14%)</td>
<td>Child's vulnerability</td>
<td>&quot;...no knowledge of what to do when lost...&quot;; &quot;...my son has no sense of danger and requires constant supervision...&quot;; &quot;...level of vulnerability...&quot;</td>
</tr>
<tr>
<td>6 (12%)</td>
<td>Public attitude to people with disabilities</td>
<td>&quot;...the general public need to be aware that there are people of different abilities in the community...&quot;; &quot;...people should be more aware, understanding and patient...&quot;</td>
</tr>
<tr>
<td>5 (10%)</td>
<td>Transport Issues</td>
<td>&quot;...my child would like to go to after school club but they won't provide transport... since we don't drive and have a two year old this is impossible...&quot;; &quot;...my son often suffers by not being able to attend after school activities due to transport issues...&quot;</td>
</tr>
<tr>
<td>5 (10%)</td>
<td>Living a long way from school or school taking children from a large area</td>
<td>&quot;...he lives a long way from school and doesn't see his school friends outside of school...&quot;; &quot;...because his friends from school live far away... he hasn't got any friends...&quot;; &quot;...the fact that her school takes children from a large area means she has no school friends that are close to our home, whom she could socialise with after school.&quot;</td>
</tr>
<tr>
<td>5 (10%)</td>
<td>Child's behaviour problems</td>
<td>&quot;...swears a lot...&quot;; &quot;...can be difficult to discipline and control...&quot;; &quot;...agression...&quot;</td>
</tr>
<tr>
<td>3 (6%)</td>
<td>Lack of confidence</td>
<td>&quot;...is very nervous of taking bus alone...&quot;; &quot;...my son lacks much confidence and needs a lot of encouragement. He lacks confidence in trying to do things for himself and going out alone...&quot;</td>
</tr>
<tr>
<td>4 (8%)</td>
<td>A dislike for social activities</td>
<td>&quot;... would really rather be left alone...&quot;; &quot;... does not like going to clubs...&quot;; &quot;... she doesn't like crowds or groups...&quot;</td>
</tr>
<tr>
<td>4 (8%)</td>
<td>Lack of support for carers</td>
<td>&quot;...lack of carers for respite...&quot;; &quot;...[the] school continually badger her father but offer no help themselves. He is 67 years old and... needs to be given help&quot;; &quot;...I'm a single parent...&quot;</td>
</tr>
<tr>
<td>3 (6%)</td>
<td>Other people for carers to care for</td>
<td>&quot;...with 3 children...&quot;; &quot;...we have a two year old...&quot;; &quot;...having 3 other children...&quot;</td>
</tr>
</tbody>
</table>
Table 2: Content of responses to question 19 and 20 that referred to service development for the promotion of children's social lives

<table>
<thead>
<tr>
<th>N</th>
<th>Themes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 (14%)*</td>
<td>More after school clubs for children with special needs</td>
<td>“…more clubs for SE…”, “…I would like to see more groups for children with special needs…”, “I would like more clubs/facilities open to children with SEN rather than always having separate groups for them as I think it is important for them to mix with all types of people.”</td>
</tr>
<tr>
<td>5 (10%)*</td>
<td>More transport/free transport</td>
<td>“…transport to and from clubs…”, “…activities …with transport pick up/drop off…”, “…free travel pass for the family so they could go out a lot more…”, “…by at least providing a freedom pass as she only uses public transport to get somewhere…”</td>
</tr>
<tr>
<td>6 (12%)*</td>
<td>More weekend/holiday clubs for children with special needs</td>
<td>“…more summer holiday schemes…”, “…maybe schools/colleges organising social events some weekends and holidays…”, “…more activities: …at weekends.”</td>
</tr>
<tr>
<td>6 (12%)*</td>
<td>After school clubs for children of mixed abilities</td>
<td>“…more… ‘normal’ clubs not just catering for those with special needs…”, “…more gatherings or meetings where they can socialise and interact with a wide range of people…”</td>
</tr>
<tr>
<td>6 (12%)*</td>
<td>More educational classes for children with special needs</td>
<td>“…self defence or yoga for people with special needs…”, “…drama group…”, “…sports clubs…”</td>
</tr>
<tr>
<td>5 (10%)*</td>
<td>One-to-one support for young person</td>
<td>“…counselling…”, “…son-rise programme…”; “…volunteers who will help her improve her communication skills…”</td>
</tr>
</tbody>
</table>
### Table 3: Miscellaneous answers

<table>
<thead>
<tr>
<th>N</th>
<th>Themes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>Miscellaneous</td>
<td>“X is having a difficult year with all sorts of problems..””, “secure help”, “she is always on her own”</td>
</tr>
</tbody>
</table>