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Parents with learning disabilities: a counselling psychology perspective

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SECTION A: INTRODUTION

Introduction

Preface

As a chartered counselling psychologist practicing within a multi-disciplinary Adult Learning Disabilities Team (ALDT), I have worked with some of the most disadvantaged members of our community. The lives of such people are typically encumbered by low socio-economic status (McGaw and Newman, 2005), stigmatisation (Jahoda, Markova and Cattermole, 1989) and poor life opportunities (O'Connor, 1992; *Valuing People: a New Strategy for Learning Disabilities for the 21st Century*: Department of Health, 2001).

From my perspective, this level of disadvantage is crystallised when a person with learning disabilities chooses to become a parent. With a child to think of as well, their limited resources are often stretched to breaking point.

I regularly worked with such families in clinical practice, who were referred into the statutory ALDT for intervention. Yet often, by the time the family had been referred, the situation was so acute that child removal was high on social services agenda.

Personally, I was troubled by the stark fact that approximately half of the children born to these parents are routinely removed into care (Booth, Booth and McConnell, 2005). I felt that if these circumstances were happening to any other group in society (certainly one with more voting power), there would be a public outcry. Yet the lives of people with learning disabilities go unnoticed in our communities. Indeed, their life opportunities lag far behind those of any other minority group (*Improving the Life Chances of Disabled People,* Cabinet Office, 2008).

I became interested in the field of parents with learning disabilities and their children. In doing so, I became immersed in the complex clinical practice and service related issues connected with these families. The work I did in this area formed the basis for this doctoral thesis.

Section B

Section B is a case study of a parenting skills program I created for mothers with learning disabilities in South Gloucestershire. Whilst I have written many individual case study reports during my training, I chose to report a case study on the development of a group program for my thesis for three key reasons:

- Parent skills training is often a required intervention for parents who have learning disabilities. It is typically delivered in group settings, rather than on an individual basis (Feldman, 1994).

- It allowed me to demonstrate the interplay between the needs of parents with learning disabilities and the services available to support them. This is particularly relevant with this population, as such parents frequently depend on and are monitored by children's social services and the ALDT's. Using the service as a focus for the case study allowed me to draw out themes pertinent to these parents in a way that an individual case analysis would not.

- Establishing this parenting program required my complete set of skills as a chartered counselling psychologist. As such, it illustrates the senior level of competence required to bring about such an intervention. I engaged social services and ALDT service managers in consultation, using research and evidence to gain agreement for the group to be created. I audited the local population, to establish the prevalence of parents with learning disabilities within our community. I designed the program content, assessed participants, facilitated the group and supervised my co-facilitators. This intervention was later published under the 'best practice' section of *Community Care* (July, 2006), the professional weekly publication for social workers.

In keeping with the wider literature on intervention with these parents, the group was based on a behavioural skills teaching model (Feldman *et al*., 1986; Feldman *et al.,* 1992). The outcomes of this program were as hoped, in that mothers demonstrated increases in identified parenting skills. As a result of the success of this group, an ongoing parenting program was subsequently established for parents with learning disabilities in South Gloucestershire.

Section C

Focusing on the needs of these mothers led me to the range of difficulties their children face. A parent with a cognitive deficit will not necessarily give birth to a child with a learning disability. Hence it is not uncommon for a child with a normal IQ to grow up within the context of learning disabled parenting.

Through clinical experience with these families, I became aware of the extent to which these children may experience courtesy stigma (Goffman, 1963), simply because of their parent's social status (Perkins, Holburn, Deaux, Flory and Vietze, 2002). It seemed that whilst parents with learning disabilities are disadvantaged members of our society, these children are even more so. I became interested in the courtesy stigma these children face and what may foster resilience for them in such difficult circumstances.

With an interest in this area, I reviewed the literature on the children of parents with learning disabilities. I was concerned to find that there were only a small handful of published studies worldwide, which investigated issues of any kind for these children (Booth and Booth, 1997; Feldman, Case, Towns and Betel, 1985; Feldman and Walton-Allen, 1997; Gillberg and Geijer-Karlsson, 1983; Kohler and Didier, 1974; McGaw, Shaw and Beckley, 2007; O'Neill, 1987; Perkins *et al*., 2002; Ronai, 1997). Only Booth and Booth (1997) had considered resilience factors in these children; none had examined resilience to courtesy stigma.

Section C consists of empirical research, which was designed to address this gap in the literature. A variable-focused approach was taken to investigating attachment and social support as protective factors; allowing for clear definitions of risk, resilience and adaptive behaviour. After a lengthy process, this study gained National Health Service Multi-centre Research Ethical Committee (MREC) approval. This allowed me to recruit mothers and children from across England, giving the investigation a country-wide perspective.

The study recruited twenty-four participants overall. The inclusion criteria were:

- Mothers with a learning disability as defined by DSM-IV (American Psychiatric Association, 1999).

- Children between the ages of 8-17 years old, without a learning disability, not monitored under child protection plans and who were living at home with their mother, who was their main caregiver.

These children were a very select group in the population at large, not least because significant numbers of them are normally removed into care, or are involved within the child protection system.

Thus the numbers in this study were small (n = 24). Nonetheless, the sample size in this research was in keeping with other studies which have been conducted in the area, where sample sizes have ranged from n = 5 (Kohler and Didier, 1974) to n = 58 (McGaw *et al*., 2007).

The research created a model for investigation using path analysis. It considered the relationships between perceived stigma, level of self-esteem, attachment related problems and degree of social support for the children of these parents. The theoretical relationships among the different variables were tested using Pearson product-moment correlation coefficient and regression. This enabled me to consider the casual nature of the relationships between each specific variable.

On the individual measures, 33.3% of children reported low self-esteem, 16.7% reported a significant level of perceived stigma and 20.8% reported attachment related problems in their relationship with their mother. Just under half of the children (45.6%) reported unsatisfactory levels of social support.

The path analysis demonstrated that attachment had a causal relationship with perception of stigma, self-esteem and social support. Children with fewer attachment problems reported less perception of stigma, higher self-esteem and increased levels of social support. It was interesting to note that the quality of a child's social support

was almost a by-product of attachment style, with those reporting more attachment related problems also indicating lower levels of social support.

Importantly, attachment was seen not only to have a causal relationship with, but act as a moderating variable in the relationship between, stigma and self-esteem. In summary, this research found that a good attachment relationship to their mother could promote healthy self-esteem for these children, and protect them from the negative effects of courtesy stigma. Good attachment was therefore seen to act as a resilience factor. This finding was in keeping with previous research, which has demonstrated secure attachment as a resilience factor for children exposed to other risks to development (Collishaw *et al.,* 2007; Kim and Cicchetti, 2004; Owens and Shaw, 2007).

This research therefore provides a contribution to the literature on resilience factors for the children of parents with learning disabilities.

Section D

Attachment-based practice requires psychologists to have a good grasp of the psychodynamic model and its theory of human development. Hence I became interested in psychodynamic intervention with people who have learning disabilities.

Section D is a review of the literature on the effectiveness of the psychodynamic model in working with this population. It found a small but growing body of knowledge, which consisted of individual case studies in addition to several empirical enquires (Beail, 1998; Beail, 2001; Beail and Warden, 1996; Beail, Warden, Morsley and Newman 2005; Beail, Kellett, Newman and Warden, 2007; Corbett, Cottis and Morris, 1996; Frankish, 1989; Heinemann, 1999; Miller, 2004; Newman and Beail, 2005; Sinason, 1992; Symington, 1981).

Although the research demonstrates some encouraging initial outcomes, a number of methodological weaknesses and lack of rigour in reporting methods compromise findings. Research in this area is slowly beginning to develop, but is clearly still in its infancy.

Conclusion

In summary, this doctorate portfolio looks at issues for parents with learning disabilities and their children from two key perspectives. It highlights the need for parent skills training and support groups for mothers, as well as attachment-based interventions to promote resilience in children. It also reviews the literature on the effectiveness of the psychodynamic model as a treatment modality for adults with learning disabilities.

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SECTION B:

DEVELOPMENT OF A SERVICE FOR PARENTS WITH LEARNING DISABILITIES IN SOUTH GLOUCESTERSHIRE:

A case study

Contents

Introduction

Even the most capable parents can find child-care a challenging and difficult experience.

Parents with learning disabilities face a range of additional pressures, the cumulative effects of which can be disastrous for both parent and child and frequently lead to the break-up of families (Feldman and Walton-Allen, 1997). The learning disabled are often socially isolated and poor (Llewellyn, McConnell, Cant and Westbrook, 1999). They frequently live in undesirable neighbourhoods (Booth and Booth, 1997). On top of these disadvantages, they also have to contend with cognitive limitations and social prejudice (Jahoda, Markova and Cattermole, 1988).

It may seem logical therefore that the children of such parents are over-represented in childcare proceedings (Booth, Booth and McConnell, 2005).

On closer examination however a more uncomfortable truth emerges. Children are sometimes removed from their learning disabled parents as they lack the simple skills to provide adequate care (McGaw and Newman, 2005). This is often due to a combination of poor education and paucity of available role models from whom to learn requisite skills (McGaw and Newman, 2005). Yet sufficient parent skills training is frequently denied to them, through a combination of poor practice and a lack of coherent collaboration between health and social services (Goodinge, 2000).

This case study documents a parent skills group I developed for mothers with learning disabilities in South Gloucestershire. While case studies are often thought of as a detailed probe into the individual, McKenna (2000) points out that they may also entail in-depth examination of an organisation - or specific phenomena within it. Therefore this case analysis sets out how health and social services agencies were brought together to create a service for parents with learning disabilities in South Gloucestershire.

Background: lack of services for parents with learning disabilities in South Gloucestershire

Over the past decade there has been a plethora of practice guidance issued to the statutory services, on working with learning disabled parents (e.g. Department of Health, 2007; Goodinge, 2000; Morris, 2003; Olsen and Tyers, 2004; Wates, 2002). There is a remarkable degree of consensus across these guidelines, which all stress the importance of joint working between child social services and Adult Learning Disabilities Teams (ALDT), when planning and delivering services to parents across the UK.

However, despite these numerous recommendations, there remains significant deficits in coordinated service provision for parents with learning disabilities across the country (Tarleton, Ward and Howarth, 2006).

In fact some have even argued that it is the failure of services to provide appropriate support that frequently forces social workers to remove children, from families that might otherwise have remained together (Ford, 1997). This is a sobering thought when the rate of child removal into care is estimated to be 50% (Booth *et al.,* 2005).

While South Gloucestershire was not atypical in the degree to which it had adopted best practice guidelines, it had been slow to develop the recommendations made by the Social Services Inspectorate (Goodinge, 2000). As such there remained no coherent or unified approach to joint working between agencies, which continued on an ad hoc basis.

In this geographical area, the main providers of care were the ALDT and the Child and Family Support Centre (CFSC), part of children's social services.

The ALDT was a multi-disciplinary team, comprising of health and social services professionals: social workers, psychiatrists, psychologists, speech and language therapists, physiotherapists, occupational therapists and learning disabilities nurses.

The nature of the CFSC was slightly different, in that it was uni-professional, consisting of social workers who were aided by child support workers. Under the auspices of child social services, child support workers were a semi-professional staff group, with no professional qualifications, although trained in child care skills by the organisation.

As with all health and social services agencies, both of these organisations were structured in what Weber called the 'ideal bureaucracy' or 'legal-rational' model (McKenna, 2000). Hence, these systems were hierarchical, with a clear chain of command. Heavily determined by government policy, such organisations are notorious for their red-tape and adherence to rules, leading to a reduced ability to manage 'special cases', such as those concerning parents with learning disabilities.

In South Gloucestershire, bureaucratic red-tape often caused referrals for parents with learning disabilities to take one of two routes:
1) They would be sent simultaneously to both the ALDT and the CFSC.
2) They would be bounced back and forth between the two services, neither believing they were best placed to meet the family's needs.

In both cases the outcomes for parents and children were frequently negative. The net result was either a replication of assessment and intervention, resulting in a confusing service delivery for parents, or a delayed intervention to the family, whilst the services decided between themselves who would take the lead. This delay could exacerbate the family's situation and contribute to crisis. Overall, these types of service delivery were exactly those observed and criticised nationally by the Social Services Inspectorate (Goodinge, 2000).

In cases that involved the mild/borderline learning disabled, the situation became even more complex. They were often referred straight to child social services by either a general practitioner or a health visitor, in which case the ALDT may not become aware of the case until it went to court for the removal of the children. By this time it was very frequently too late for the identification of a learning disability in the parent to have an impact on the outcome of proceedings.

In some instances there were further layers of complexity behind this delay. The eligibility criteria for the ALDT was known to be restrictive and the label of learning disability to be stigmatising. Consequently professionals from other services were cautious about referring to the ALDT and there may even have been resistance from the service users, if they perceived themselves potentially stigmatised by the outcome.

As a chartered counselling psychologist working full time in the ALDT, I became increasingly interested in the issue of service provision for such families. I was particularly struck by the level of injustice these families faced. I joined a local special interest group in parenting and learning disabilities, which included key professionals of the ALDT and the CFSC. Over several months, we explored different options which could improve service delivery to parents in South Gloucestershire.

The CFSC reported a significant number of the children referred to them had parents who were cognitively low functioning and who lacked basic care-giving skills. Furthermore, they had found their attempts to include these parents in mainstream parenting skills programs (such as the Webster-Stratton, 1998) were largely unsuccessful. There had been several complaints from parents that they did not feel accepted in these groups and therefore felt stigmatised when they had to admit they did not understand the material being taught.

The fact parents with learning disabilities struggle with mainstream parenting programs is well established. McGaw and Newman (2005) point out that these parents do not benefit from such groups when their particular needs are in the minority.

Consequently, I took the lead on developing a proposal for a parenting skills program to meet the needs of parents with learning disabilities in South Gloucestershire. This provided an opportunity to foster collaboration between the ALDT and the CFSC, which was seen as a priority, in order to meet the good practice requirements set out by the Social Services Inspectorate (Goodinge, 2000).

Getting started: an audit to establish the prevalence of parents with learning disabilities in South Gloucestershire.

The first step was to establish the size of the local population of parents with learning disabilities. This I achieved by conducting a caseload audit of both teams.

I first attended the ALDT team meeting and asked professionals to identify parents who they considered to have a learning disability along side concurrent problems in parenting skills.

Professionals within the ALDT defined parental learning disability on the basis of the medical model DSM-IV criteria (American Psychiatric Association, 1999). This criteria was:

- Intelligence Quotient (IQ) below 70, as measured by standardised intelligence tests.

- Significant impairments in adaptive and social functioning.

- Onset before the age of 18 years old.

This process identified nine parents from the ALDT who had a diagnosed learning disability together with reported deficits in parenting skills. These parents were mostly single mothers, living in disadvantaged neighbourhoods, receiving little or no support.

Having identified the parents from the ALDT, I then attended CFSC team meetings on two separate occasions. I requested each professional audit their own caseload to identify those whose difficulties and needs were in line with parents from the ALDT.

As the CFSC did not use the medical model of diagnosis, the agreed audit criteria for their population of parents was:

- Diagnosed with a learning disability or cognitively low functioning in their professional opinion. Where possible this included a review of case notes to establish schooling.

- In need of significant support with day-to-day living tasks, including parenting skills.

This process identified approximately thirty parents from the CFSC who met these criteria. In addition, these parents shared the same socio-economic status as the ALDT parents.

Hence, there were strong similarities between the ADLT and the CFSC parents with regard to functioning, socio-economic circumstances and social support. The only significant difference between them appeared to be a lack of formal diagnosis in the CFSC group.

It seemed likely that CFSC parents were probably in the mild/borderline learning disability range, who had managed their lives without the need for support of specialist learning disabilities services. However, the pressures placed upon them by parenthood had brought them to the attention of social services.

Consequently, the audit I carried out revealed an extensive population of low functioning parents who had no formal diagnosis of learning disability.

This raised questions around the extent to which the strict ALDT eligibility criteria of DSM-IV diagnosis was ruling out parents who were closer to the cusp of normal functioning than those with more severe disabilities. This finding is in keeping with Goodinge (2000) who identified that, across the country, ALDT criteria was too restrictive, resulting in an unmet need for this population of parents.

I fed back the audit findings to the learning disabilities special interests group, as well as the ALDT and CFSC managers. After discussion, we concluded it was not feasible

to formally assess the thirty parents identified by the CFSC, using DSM-IV criteria. There were two main reasons for this.

Firstly, it was felt that the parents themselves would not welcome such assessment. The label of learning disability is stigmatising and they had managed thus far in their lives without it.

Secondly, it was clear that ALDT service managers were concerned that they were not resourced to meet the needs of another thirty service users.

Personally, I felt that had I proposed to assess this 'undiagnosed' population for a formal learning disability, I could threaten the opportunity to establish a parenting skills group at all.

Despite the difficulties with DSM-IV diagnosis, it was important that we clarified the existence of a learning disability for eligibility to the parenting group. This was in order to ensure that our interventions were designed from the evidence base within which we possessed expertise professionally.

Therefore in order to identify parents with learning disabilities, but navigate our way beyond ALDT eligibility criteria, I turned to the social systems definition of learning disability (Mercer, 1973; Feldman, Case, Towns and Betel, 1985).

From this perspective, a 'diagnosis' of learning disability is made on the basis of professional opinion. This opinion is founded on assessment of educational history, interview, and observation that support with daily living is required.

Hence, all parents were assessed for the group on the basis of this social model definition of learning disability. Using this definition of learning disability was in line with good practice recommendations from the Social Service Inspectorate (Goodinge, 2000). However, from the ALDT management perspective, parents eligible for this group were not therefore automatically entitled to the rest of the services and benefits offered by the ADLT, such as occupational therapy or Disability Living Allowance.

Developing the group: agreeing division of resources between adult and children's services.

After establishing the prevalence of the population and agreeing the eligibility criteria for the group, I again met with service managers from the ALDT and the CFSC. Through consultation I secured agreement that:

- A parenting skills group would be created. This would run as a pilot initially, with a view to making it a permanent service if it was deemed to be successful.

- Services would work together.

- Relevant resources from both services would be pooled in order to facilitate the running of the group.

The CFSC provided a group room in the children's centre and a staffed crèche. The ALDT provided funding for transport to and from the group.

In terms of staff, the CFSC assigned two child support workers to the project, both of whom possessed expertise in parent skills training.

ALDT managers were supportive in allowing me ring-fenced time to develop and run the group.

I brought broad base of expertise to the project – in learning disabilities and parenting, psychological models, research methods, consultation, teaching and supervision skills. I was also an experienced group facilitator.

The role of child support worker is a semi-professional one and although both the support workers had a solid set of skills around parent training, I was considered the senior clinician by the ADLT and the CFSC.

Consequently, I ran the project as a whole and was the lead facilitator in the parenting group itself, with the child support workers co-facilitating. I provided supervision to both these staff.

This inter-agency working therefore created an additional service for the ALDT and the CFSC to offer parents in the locality. Smith (1992) used set theory to depict the implied relationships in inter-professional work. Figure 1 below illustrates the association between the ALDT and the CFSC in terms of the parenting skills group:

Figure 1: model of inter-professional working between the ALDT and the CFSC

A = ALDT
B = CFSC
C = Group for parents with learning disabilities
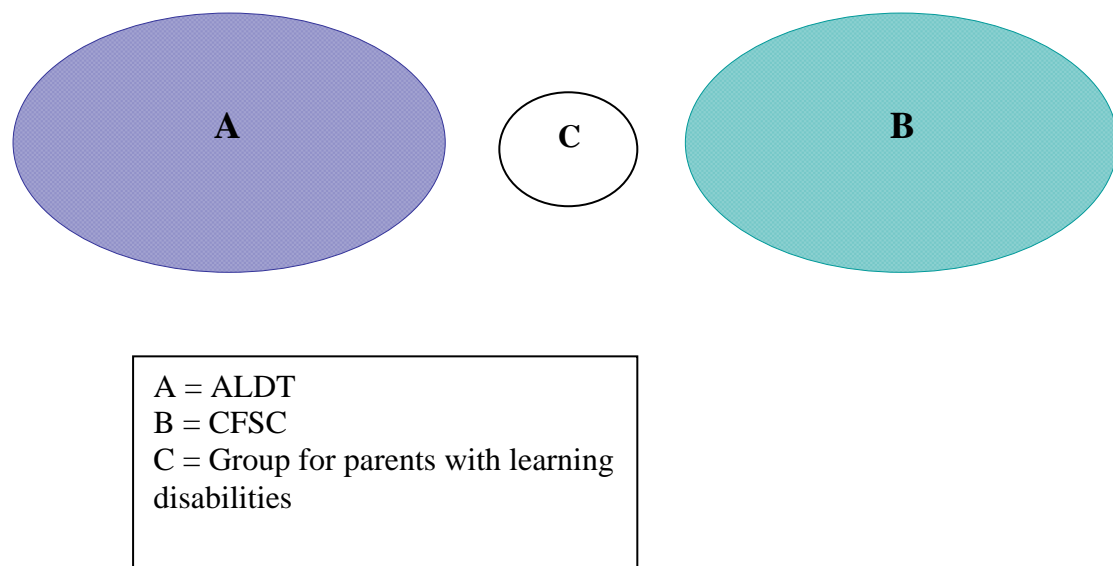
Subsequently, the development of this group can be seen as a multiplicative effects model. Rawson (1997) describes this model as one where:

> '… efforts are combined to achieve more than would have been possible by simply adding contributions together. Inter-professional work generates new potentials and enhances individual contributions.'

By joining forces we were able to create and deliver a new service to parents, which neither agency could have provided on its own.

Referral to the group

I received referrals from the child social work teams, health visitors, midwives and the ALDT across South Gloucestershire. The inclusion criteria were:

- Parents who met the social systems definition of learning disability (Mercer, 1973; Feldman *et al.,* 1985).

- Parents with deficits in child-care skills as assessed by a health or social services professional.

- Couples who were pregnant or with a child under the age of twelve years old. This age was the cut off point as the CFSC only provided a service to children up to the age of twelve years.

I received thirteen referrals in total; six of these represented mothers who were either pregnant or had a young baby. After discussion with my co-facilitators and service managers, we decided to pilot the first group with these six mothers. Looking at parenting issues for new born babies allowed us to think in terms of early intervention, as well as provided a sensible start point for the program as a whole.

Assessment for the group

I made an initial visit to all six mothers to explain the aims of the parenting program and invited them to ask questions.

I visited a second time to carry out assessment for the group, which was done using the Parent Assessment Manual (McGaw *et al*., 1999). This measure is considered the gold standard in terms of parenting assessment with people with learning disabilities. It consists of several different components, which can be used separately or in conjunction with one another. For the purpose of these interviews I used the Parent Questionnaire. This structured interview asks about the mothers parenting skill needs, as well as their relationship and family history.

During the assessment each of the mothers reported varying degrees of skills deficits around parenting skills such as feeding, weaning, crying, handling, nappy changing, sleep, and play. Parents were aware of their particular difficulties, as their health visitors, social workers or child support workers had assessed their parenting skills and highlighted these specific issues as problem areas prior to referral to the group.

Between them, two of the mothers had five children previously removed into care due to neglect. All six mothers reported dysfunctional family histories, with poor parenting models and had been victims of maltreatment during childhood. The majority were single parents and one was in a marriage that was documented as physically abusive by social services. Each mother reported a high level of social isolation and had little by way of practical or emotional support. One had a history of chronic depression and another had a history of drug abuse.

Thus, every one of the mothers assessed for the group reported poor support networks and were heavily reliant on services for support.

Each mother indicated they would like to join the group to meet other women in a similar situation to themselves. As the development of the group was extended over

time, verbal consent to participation was gained, rather than individual signatures recorded.

Table 1 below illustrates the age and key reason for referral to the group for each mother assessed.

Number	Age of mother	Age of child	Parenting skills concerns
1	22 years	6 weeks	Previously 2 children removed into care for neglect. Issues with menu planning, safety in the home and cleanliness. Diagnosis of depression. No partner; socially isolated.
2	36 years	7 months pregnant	Concerns autistic spectrum disorder would make it hard for her to meet baby's needs. No partner; socially isolated.
3	17 years	2 months	Lack of knowledge around baby's basic developmental needs: play & stimulation. No partner; socially isolated.
4	21 years	18 months	Feeding, nappy changing, safety in the home, cleanliness. In an abusive marriage; socially isolated.
5	24 years	5 months	3 previous children removed for neglect. Lack of awareness of most basic parenting skills. Ex-heroin user. No partner; socially isolated.
6	28	3months	Socially isolated. Problems with self-esteem. Lacks confidence in parenting abilities.

Formulation

Neglect is the most common reason for child removal into care with parents who have learning disabilities (Booth, Booth and McConnell, 2005). McGaw and Newman (2005) draw a clear distinction between neglect by omission of care as opposed to the wilful, purposeful neglect of a child. McGaw and Newman (2005) suggest the majority of children removed from their learning disabled parents have suffered neglect by omission because their parents lack the simple skills to provide adequate care.

Mothers assessed for the current group all indicated skills deficits in basic parenting tasks. Their failure to provide such care had been deemed critical by social services and their children were considered to be at risk of neglect. As a result, each of their children were being monitored through child protection plans at the time of this intervention. Professionals involved with the families considered these skills deficits to be due to mothers' lack of experience, lack of education and dysfunctional family histories. Consequently their parenting difficulties were suspected to be borne of ignorance, leading to acts of neglect by omission.

Evidence suggests that parents with learning disabilities can improve care-giving skills through group and individual parent training programs (Feldman, 1994; Hur, 1997). However, research into the effectiveness of parent skills training demonstrates a number of methodological weaknesses. For example, studies have been criticised for their recruitment methods as many have included only those referred for intervention once they have reached crisis (Tymchuck, 1992a). Consequently participants represent a skewed sample not representative of parents with learning disabilities as a whole. Investigations have also varied in terms of their assessment of parenting skills, with some focusing upon parent-child interaction (Tymchuck and Andron, 1992), where others have focused on skills such as bathing and feeding (Feldman, Case and Sparkes, 1992). Furthermore, there is no concrete definition of adequate parenting (Tymchuck and Feldman, 1991) and few use standardised measures of assessment (McGaw, 2006), hence it is difficult to compare effectiveness of interventions between studies.

Despite these methodological flaws, there is agreement in the literature that parents are able to develop child care skills through training (Murphy and Feldman, 2002). Indeed, the document *Good Practice Guidance on Working with Parents with a Learning Disability* (Department of Health, 2007) recommends that services to people with learning disabilities provide training in parenting skills where necessary.

The mothers who were invited to join the current parenting group had clearly identified skills deficits relating to menu planning, safety in the home, feeding their child and nappy changing. Several mothers also had identified deficits in parent-child interaction skills; lacking awareness of how to play with and stimulate their child. Two particular studies by Maurice Feldman and colleagues have demonstrated effective intervention with mothers with respect to developing these specific parenting skills (Feldman *et al*., 1992; Feldman *et al.,* 1986). Consequently these two studies were used to inform the evidence base for this intervention.

Feldman *et al*., (1992) carried out a study with eleven mothers with learning disabilities. To be eligible, mothers were required to have an IQ of less than 80, and to have previously been considered as learning disabled by the educational system or by agencies involved in supporting the family. The study took a multiple baseline design and included a matched control group. Mothers were taught skills relating to bathing their child, treating nappy rash and cradle cap, cleaning baby bottles and preparing formula. Training sessions were conducted weekly in the mothers' home. Feldman *et al.* (1992) used a range of methods to teach requisite skills - including verbal instruction, pictorial prompts, modelling, feedback, praise and rewards. Overall, all mothers were found to increase their child-care skills as a result of training. Across all the skills, the percentage correct performance increased from 58% in baseline to 90% in training. At follow-up 91% of skills had been maintained.

There were a number of limitations to this study. Mother's with IQ range up to 80 were included; hence the sample comprised several parents who did not meet a formal diagnosis of learning disability of IQ below 70, as defined by DSM-IV (American Psychiatric Association, 1999). Intervention was carried out weekly in participant's homes. This type of intervention is costly and uses a large number of resources, not necessarily available to other services. The number of participants was small (n =

11), which reduces the statistical generalisability of findings. Furthermore, mothers who participated were all referred by social services, due to problems with parenting skills. Their skills deficits may therefore may not be representative of parents with learning disabilities as a population. Nonetheless, mothers who participated in Feldman *et al.'s* (1992) study shared similar skills deficits, as well as referral sources, to the mothers included in the current group. As such, the outcomes from Feldman *et al.'s* (1992) study were seen as relevant indicators as to what may be achieved with this group in terms of parent skills training.

Another study by Feldman *et al.* (1986) focused on teaching mothers with learning disabilities to play with and stimulate their children. Such parenting skills are particularly significant, as lack of adequate cognitive stimulation has been shown to place children at risk of developmental delay (Feldman *et al.,* 1985). Feldman *et al.* (1986) split their study into two parts. In the first part, Feldman *et al.* (1986) carried out a comparison between eight learning disabled mothers and eight non-learning disabled mothers as a matched control group. Learning disabled mothers were chosen for the study on the basis of having an IQ score of less than 85, as well as having previously been labelled as learning disabled by the educational system, or by social services agencies. Mothers were assessed and compared on how much they engaged with their child, with respect to play, praising, talking, making eye contact with and imitating the vocal noises of their child. Feldman *et al.* (1986) found that the learning disabled mothers were less likely to engage with their children than the control group, particularly with respect to praising and imitating their child.

The second study by Feldman *et al.* (1986) included seven learning disabled mothers, with a mean IQ of 71. Baseline measures were recorded by observing mothers in terms of how much they praised, talked to, looked at, imitated and played with their child. Intervention was delivered in a group setting via discussion, modelling, observing mothers and giving them constructive feedback with suggestions for how they may improve their interaction. In general, praise and imitation proved to be the major deficit areas, although all mothers showed increases in the target skills after training. These gains were maintained at follow-up over a 5-10 month period. Feldman *et al.* (1986) also found that children's vocalisations increased after parent training, although the amount of increase varied.

The limitation of this study was the small sample size (n = 7), which restricts the generalisation of findings to the wider population of parents with learning disabilities. Furthermore, parent skills were assessed by observing the mother. As mothers may have a vested interest in performing well under such conditions, this may generate unreliable data. A more accurate baseline would be gained by interviewing family members in addition to observing the mother. Nonetheless, this study presents encouraging findings with regards to teaching mothers to play with and stimulate their child and, as such, was considered to be pertinent to the mothers assessed for the current parenting program.

Although methodological weaknesses were noted in the above studies, these are not uncommon in research into the effectiveness of parent skills training in this population (Hur, 1997). The studies by Feldman *et al*. (1992) and Feldman *et al*. (1986) detailed interventions so closely relevant to the mothers in this group that, despite the limitations identified, it was considered appropriate to draw on them as an evidence base for this parenting program.

In addition to parent skills deficits, the each of the mothers assessed for the current group reported a significant lack of social support. This finding is in keeping with the wider research, which has shown these mothers are amongst the most socially isolated in our communities (Llewellyn and McConnell, 2002). Lack of support in the parenting role is a critical issue for mothers with learning disabilities. Tymchuck *et al*. (1990) found that the absence of suitable familial and social support for a mother is actually *predictive* of child neglect. Thus the mothers included in our program may have been especially vulnerable to neglecting their child due to a lack of appropriate social support.

The emotional support offered by parenting programs designed to meet the needs of the learning disabled population have been shown to mitigate against some of the effects of parenting in isolation (Heinz and Grant, 2003). Mixing with peers from the same social group provides the opportunity for social skills learning as well emotional support, which both Llewellyn (1995) and Tarleton *et al.* (2006) point out is vital for such isolated individuals. Therefore delivering skills training in a group setting offered the additional benefit of peer support for these mothers.

Intervention

Scope of the group

I developed the scope of the group by drawing out the key shortfalls in parenting skills that were highlighted in the assessment and initial referral letter. The child support workers and myself then met to clarify how each of these skills would be taught.

Overall, I explored how the child support workers would normally teach parenting skills to clients without cognitive limitations. Then I adapted their teaching methods to meet the cognitive style and communication difficulties of our parents.

To do this I used the Department of Health (2007) guidelines on group work with learning disabled parents. I split teaching tasks into 2-3 skills at a time and wrote handouts in simple everyday language. I identified a range of mediums to support the teaching; including pictures, checklists, simple written explanations, videotape, role playing, modelling, discussion and games. I put heavy emphasis on repetition of skills to enhance learning and wherever possible to use concrete examples from the parents' everyday life. Table 2 below illustrates the parenting program:

Session number	Session theme
Session 1	Getting to know each other
Session 2	What we find difficult about parenting
Session 3	What support we have to help us parent
Session 4	Feeding
Session 5	Weaning
Session 6	Crying and screaming
Session 7	Handling and holding
Session 8	Nappy changing and sleeping
Session 9	Play and stimulation
Session 10	Play and stimulation
Session 11	Play and stimulation
Session 12	Individual summary and plan for future

The model for intervention was largely skills teaching based, with opportunities to receive positive support, praise and feedback. While I led each group, I took full responsibility for teaching in sessions 1-3 and then the final session 12. I drew on the expertise of the child support workers for teaching specific parenting skills in sessions 4-11.

Overall, the model for intervention had two complementary aims. The primary aim was to develop mothers parenting skills for their infants. The second was to provide emotional support in a safe and non-judgmental climate. These two aims had immediate, intermediate and long term goals. Table 3 below illustrates the differing levels of intervention the group provided:

Intervention	Immediate	Intermediate	Long term
Parenting Skills	Provide children with safer physical care. Increase level of stimulation and positive interaction between mother and child.	Have healthier, more positive parent child relationships.	Mother and professionals involved are confident that childcare is 'good enough'. Child meets developmental milestones and thrives.
Emotionally supportive environment	Mothers to feel accepted and respected	Mothers to share their experiences with one another and reduce sense of isolation.	Increase social interactions, ability to express themselves, self-confidence and self-esteem. Increase awareness of available social support services within the community.

Overview

The sessions ran for twelve weeks, as a closed group. Of the six mothers identified, only one had a partner. Consequently, for the purposes of the pilot group, it was agreed that mothers only would be included. However, it was noted that future groups should include fathers.

Group members were expected to make a commitment to attend every session. I led each group, with one of the child support workers co-facilitating with me. The sessions ran on the same day and time each week, lasting one and a half hours, with breaks built in for tea and coffee. Funding for public transport was provided for each mother to attend and they were able to leave their children at the crèche facilities in the CFSC whilst they were in the group sessions.

I explained the boundaries of confidentiality at the beginning of every session. It was agreed that everything that was said within the group would remain private, with the normal caveat of any issues of risk or harm to self or other. General feedback to the original referrer and to childrens' social workers would be agreed with each mother beforehand. Similarly, it was agreed that any concerns about their children would be

discussed privately with the respective mother before a report to social services was made.

Throughout each group I was conscious to provide multiple opportunities for mothers to observe others, practice target skills and receive feedback on their performance. Frequent, regular positive re-enforcement for demonstrated performance of new skills was important to foster confidence, as was the opportunity to succeed. Whilst the sessions were structured, the group was willing to adapt to suit the needs of the parents on any given day. The most important focus we collectively maintained was on building parents strengths rather than focusing on their weaknesses.

Sessions 1-3

The first session was spent getting to know one another and establishing some ground rules for the group process, such as being on time and listening to each other. The beginning of Session 2 was dominated by the experience of a mother who had two previous children removed into care. She told the group that by the time her 2 year old and 4 year old boys had gone into care, they were developmentally delayed, physically neglected and under weight. She claimed they had eaten only eaten toasted bread for two years. One of her children had developed substantial intestinal problems that resulted in a lengthy hospital admission.

From her description it sounded as if this mother had been suffering from severe depression at the time, yet had avoided seeking treatment from her G.P. as she was afraid she would come to the attention of social services. However, her son's hospital admission had revealed the extent of her problems and child social services had ultimately become involved.

The removal of her children had left her desperate; she told the group of her deep feelings of guilt, shame, hopelessness, despair and rage. I encouraged the other mothers to relate to her experience, but they clearly found it difficult to know what to say. She had faced that which they feared most – having her child removed from her care. As the group was not the appropriate environment within which to process her losses in depth, I was able to signpost other services to her for individual therapy.

However, this early experience further highlighted to me the need for emotional support for these mothers.

In the second part of session 2 the group focused on difficulties they had experienced with parenting. They reported a range of highly stressful issues; such as being constantly assessed by social services, being socially isolated and feeling stigmatised, living in poverty, being physically abused by a boyfriend, being spat at and verbally abused by children on their estate. One mother reported that strangers had come up to her in the street and told her she was not supposed to have a baby. Another said that family members had told her she was not capable of being a mother, because she was 'stupid'.

During session 3 I encouraged members to clarify what support they had in their lives to help them parent. I spent time teaching the benefits of emotional support and how it could enhance their parenting ability, and asked the group to identify potential networks in their lives. Mothers could see several different avenues by which they could garner further support, such as mother and baby groups, the local church, joining specific courses or a club. They also explored whether they had existing family and friendship networks that could be developed further.

These mothers were able to recognise that they could do more to take advantage of the potential support around them. Yet, it was noteworthy that practical issues such as not having transport or enough money were often reported obstacles to accessing support networks.

Sessions 4-8
Feeding infants was taught by practical demonstration on how to sterilise a bottle and make up a feed. Each mother then practiced using the baby simulator (PSD Import Agency), to learn what position to sit the baby in and how to wind after feeding. Everyone managed this without too much difficulty, collectively illustrating more ability that would have been deduced from their assessment or initial referral letter.

In session 5, weaning and menu planning was taught using verbal and pictorial prompts as well as modelling and rehearsal. This session indicated to us how lacking in nutrition most mothers diets were. Living on benefits, they tended to choose cheap food which was high fat. It was clear that having little money made it harder to buy healthy food.

The next two group sessions focused on why babies cry and how to hold and handle an infant. It was apparent that some mothers did not see why their baby might cry – beyond needing feeding or changing. This drew our attention to how much more able these mothers were to grasp the concrete skills, like making a bottle, whilst being less aware of a baby's more abstract emotional needs.

Session 8 delivered skills training on nappy changing and sleep. These were taught through practical demonstration, using the baby simulator. Each group member put a nappy on the 'model' baby several times. Again, all except one of the parents demonstrated competence in this skill without teaching.

During this session we were reminded that competence with one parenting skill did not indicate overall ability. The mother who had shown the most skill so far told us how she was going to potty train her baby at 6 months old (when typically babies are potty trained at around 2 years old). This raised issues for us around the lack of knowledge these mothers had about the developmental stages of an infant/baby/child's life.

During session 8 a crèche worker notified me that one of the babies had a mark on her face, which looked like an adult bite. The crèche worker had also noticed a bruise on the baby's upper arm, above the elbow. At the end of the group I took the respective mother into a private room. I explained what had been observed and that I would need to pass this information to her daughter's social worker. This was difficult, as she had come a long way since the start of the group in terms of self-confidence and to have such an event happen was a great pity. She was clearly upset, but appeared to accept the inevitability of the social services investigation to follow.

Personally, I was concerned that this mother may refuse to come to any further group sessions and was surprised when in fact she did continue to attend. At the time I had felt this indicated the degree to which she needed the support offered by the group, despite the above incident. Sadly, several weeks after the ending of the group, I was informed that this child had been removed into care. Reflecting on this outcome, I believed her continued attendance had in fact been a cry for help.

Session 8 also sparked an unrelated conversation amongst the other mothers about their experiences of child protection case conferences. They were clearly able to empathise with each others in a way that, as professionals, we simply could not. Many of their complaints centred around not understanding what was being said in the meetings and feeling fundamentally criticised for being learning disabled. They highlighted the need for appropriate advocacy and accessible information to be provided during child protection case conferences.

Their discussions drew our attention to the importance of delivering a parenting program such as ours, in order that these women have a forum to come together and learn from each other.

Sessions 9-12

I led a group discussion on the importance of positive mother-child interactions, exploring why imitating a baby's facial expressions and noises were crucial in terms of social and language development. We watched a DVD on mother-child interaction in the early developmental stages to aid our parents understanding.

The group discussed how they play with their baby, things that work well for them and things they find difficult. We used selections of toys to discuss the importance of colour, texture and noise as well as highlighted the need to check for age-appropriateness.

Session 11 was dedicated to mothers playing with their own children from the crèche, which gave us the opportunity to give positive feedback and discuss ideas for play at home.

All the mothers appeared competent in this regard. However, I felt that the setting within which they were playing with their child was slightly artificial. Each mother was keen to shown off their baby to the others and keen to demonstrate their ability to me and my co-facilitator.

On reflection I felt the context may be distorting the real picture. We know that one of the most common issues in parenting provided by the learning disabled is a lack of infant stimulation. Therefore, these mothers may have been energised by the group setting, in a way that they would not be on a normal day at home with their baby.

The final session consisted of a review of the skills learnt and a pictorial summary of the twelve weeks was given out. Certificates of achievement were also presented to each group member. I requested feedback on the group as a whole by asking mothers to rate each group using a Likert scale and to comment on:

- what they enjoyed the most
- what was most helpful
- what they did not like

A few of the mothers also exchanged phone numbers, indicating that perhaps some further friendship may develop.

Follow-up

I carried out a follow-up appointment at six weeks by observing mothers in their own homes and by requesting feedback from the original referrers. This indicated developments in parenting skills had been maintained by all but one, and several had made attempts to improve their social network.

After the follow-up, feedback was given to children's social services on each mothers' overall achievements in the group. This feedback was first discussed with the mother, before a report was written to the respective social worker.

Discussion and conclusions

I was personally motivated to establish this parenting group as a direct result of my clinical work with these parents. I felt strongly that the lack of service provision in South Gloucestershire was directly contributing to their involvement with child protection agencies. At its worst, I felt the lack of service provision was contributing to child removal into care.

I was able to create this group by taking a consultative role between the children's and adult's services. Service managers welcomed my involvement, as they were keen to meet some of the recommendations made by the Social Services Inspectorate (Goodinge, 2000), with respect to interventions for parents with learning disabilities. I was therefore able to capitalize on a degree of good will which existed within the management team, towards initiatives such as parenting skills groups for this population.

In effect, the Social Services Inspectorate recommendations gave permission for the normally bureaucratic and functionally separate ALDT and CFSC to join together for the purposes of this group.

Pooling our resources and manpower lead to a solid piece of inter-professional work. Rawson (1997) points out that such collaboration challenges professionals to rethink their purpose and establish the most effective means of practice, which can reduce duplication and waste by expensive teams. As a service for parents with learning disabilities, we were able to provide coherent assessment and intervention, moving away from the previous method of duplicating both within the ALDT and CFSC.

Using the social systems (Mercer, 1973) as opposed to the medical definition of learning disability allowed us greater flexibility in identifying the population of parents with learning disabilities. However, in doing so, our group may have included mothers whose IQ would have fallen in the borderline or low average range (IQ 70-89), although their adaptive behaviour skills may still have been limited. As such it might be argued that some of the mothers who took part in this group did not have a

learning disability as defined by DSM-IV (American Psychiatric Association, 1999). Nonetheless, using the social systems definition of learning disability is in keeping with the wider research in his area. Indeed, Feldman *et al*. (1986) and Feldman *et al*. (1992) included mothers with IQ up to 85 in their studies.

The group was successful in retaining the commitment of its members; which many parenting programs find difficult to achieve (Heinz and Grant, 2003). Yet it is possible our mothers may have felt compelled to join and to attend the group (even though participation was voluntary), as each of their children were being monitored under child protection plans. Hence not doing so may have harmed their position with social services. In this respect, mothers included in this group may not be seen as representative of parents with learning disabilities as a whole, as not all children will be subject to child protection.

The group fulfilled its first aim of teaching parenting skills identified at assessment, thereby enhancing parenting competence. The outcomes of this group were therefore in keeping with previous research, which has demonstrated parents with learning disabilities are able to improve child-care skills through intervention (Feldman *et al*., 1992; Feldman *et al.,* 1989).

However, during the process of the group it was noted that mothers displayed more competent parenting skills in most areas than would have been predicted from assessment. This finding was surprising. One reason for this might be that the group setting energised these mothers in a way that being in their own home would not. Yet this seemed an insufficient explanation, as their parenting skills deficits had been of concern to social services over a period of time, so much so their children were considered at risk of neglect.

Alternatively, this discrepancy might be explained by two other factors. First, it was possible that professionals were taking an over cautious approach to assessment of these mothers due to parental learning disability, an issue noted in the wider literature (Booth, 2000). Second, it might suggest that mothers' competence in basic parenting skills was intermittent, leaving professionals unclear as to their actual ability. Such inconsistency in care-giving might indicate an underlying attachment problem

between mother and child that was not the focus of either the assessment or the intervention with these mothers. As Howe (2005) describes, neglectful care-giving is often characterised by passive and unresponsive behaviour in the mother. It is possible that professionals interpret this fragile care-giving as due to parental learning disability and ignorance as to what is required of them. However, the real cause of the difficulty might lie in the mothers own dysfunctional history of being parented, which has left them unable to provide the conditions necessary for their child to form a secure attachment. In such cases successful mother-child interaction may be observed as intermittent. If this is the case, interventions designed to address attachment may be an important precursor to parent skills training. This issue was noted and considered important to take forward with regards to future parenting assessments with these mothers.

Nonetheless, during the group program, it was also the case that parenting competence tended to be stronger on practical skills (such as bottle feeding and nappy changing) and weaker on emotional skills (such as why babies cry). This may have indicated that mothers easily understood concrete information as opposed to their baby's more abstract needs – such as to be soothed when crying. Mothers did clearly indicate knowledge deficits in terms of child development (such as when a child should be potty trained), as well on achieving appropriate food and nutrition for themselves and their child on a limited budget. These issues were noted for greater inclusion in future parenting skills groups.

The group fulfilled its second aim of creating an environment in which mothers felt emotionally supported by us and by each other. This enabled them to grow in confidence and to reduce their sense of social isolation. Some of the mothers also indicated a desire to continue with their friendship once the group had come to an end. Heinz and Grant (2003) report a similar experience with their parenting program. They found that the opportunity to socialise with and receive support from peers was the main reason mothers continued to attend their parenting group. Reducing social isolation is a valuable intervention provided by parenting projects. As Feldman *et al.* (2002) demonstrate, a satisfactory social support network can not only mitigate the effects of parenting related stress, but have a positive benefit of parent-child interaction.

In fact, feedback from the group members themselves indicated that emotional support was the most valued component of the program. During the group all of the mothers had drawn attention to their limited social support networks, and how simple things such as the lack of money for a bus fare could restrict their ability to stay in contact with their friends and families. This highlighted the potential for a parenting group such as ours to act as an important support for these isolated mothers, particularly as they were able to access funding for transport to attend it via social services.

Feedback from the mothers also drew attention to difficulties they have to negotiate when attending child protection conferences. Group members benefitted from being able to discuss these experiences with one another, which prior to the group none had been able to do with a peer. Mothers also highlighted the need for information to be made accessible to them within such meetings, in order that they can fully engage in the processes by which decisions are made about their children. Indeed, this is echoed in the document *Good Practice Guidance on Working with a Parent with a Learning Disability* (Department of Health, 2007), which advises that information at child protection conferences should be delivered in a format which parents with learning disabilities can understand.

As a result of the group intervention, mothers improved their parenting skills with respect to menu planning, safety in the home, bottle feeding, nappy changing and playing with their child. However, professionals' observations of parenting skills were used as the baseline and outcome measure in this intervention. Although this is in keeping with other similar studies (Feldman *et al.,* 1986; Feldman *et al*., 1992) the inclusion of a standardised measure, or feedback from significant others involved in mothers' daily lives, would have provided more robust data in this regard. Such assessment might be particularly important if professionals' concerns about parental learning disability, and/or child attachment issues are clouding the picture with regards to an accurate assessment of skills competence.

Throughout the twelve weeks I supervised my co-facilitators on an ongoing basis. One of the themes of supervision was the balance we had to strike between providing a safe, supportive environment for mothers, whilst observing our child protection

responsibilities and ongoing relationships with child social workers. Such tensions between policing and enabling roles for professionals involved with these families are reflected in the literature (Booth, 2000). These conflicting responsibilities were managed within our parenting group by being clear with mothers and social workers what our processes were in this regard, right from the start of the program. In keeping with this, the child protection concern I responded to in session 8 was first discussed with the mother before the information was passed to social services. Although distressing, having been clear about the procedure I needed to follow enabled this incident to be addressed effectively and with minimum disruption to the group as a whole.

During supervision I frequently drew on a psychoanalytic model to make sense of underlying dynamics within the group. It was notable that in the transference we often felt cast as the parents. We were mindful of this and made efforts to draw group members' attention to this dynamic when it was taking place. In the counter-transference we were able to re-enforce the mothers 'parent-self' and foster confidence in their ability.

The supervision process also enabled us to recognise our inherent bias towards either mother or child needs, depending on whether we worked for the child or adult services. Through supervision we were able to prevent splitting within the team of facilitators. Goodinge's (2000) report illustrates the importance of managing this dynamic, as professional bias' towards children or adults in this way have been found to compromise the success of interventions.

As a counselling psychologist I brought a broad set of skills to developing this group. It is a pity therefore that learning disabilities has held a Cinderella status within the field of counselling psychology. To some extent this might be understood as reflective of a historical lack of emphasis on the emotional lives of people with learning disabilities, by both services and society as a whole (Bender, 1993). However, with increasing numbers of counselling psychologists working within the field of learning disabilities, training courses should look to include the needs of this population within their syllabus.

In conclusion, this pilot parenting skills group was successful in its aims to:

- promote parenting competence
- provide emotional support for mothers with cognitive limitations

As a result of the success of this group, I was able to secure agreement from both adult and child services that a parenting skills group would be offered on an ongoing basis in South Gloucestershire. This is in line with good practice guidance from the Social Services Inspectorate (Goodinge, 2000) and the Department of Health (2007).

In terms of service agenda, it was considered that directing resources at such early intervention strategies may (in the long-term) have some moderating influence on the numbers of children removed into care for reasons of neglect by omission in this locality.

Good practice statement

Mothers who participated in this group gave their verbal consent for the program to be written up as a case study for the qualification of Doctor of Psychology. They also gave permission for it to reported in *Community Care* magazine, the publication for social care professionals, who featured our parenting group as an example of 'best practice' (*Community Care*, July 2006). A copy of this article can be found in Appendix A. All mothers who took part were also given a copy of this publication.

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SECTION C:

MOTHERS WITH LEARNING DISABILITIES AND THEIR CHILDREN:

Attachment as a resilience factor

Abstract

Introduction: Parents with learning disabilities belong to a disadvantaged group in society. A consequence of which their children may be at risk of a range of adversities, including courtesy stigma. Research has shown that certain factors can promote resilience for children who grow up in difficult circumstances, yet there has been little enquiry of this kind with the children of parents with learning disabilities. This research examined the role of attachment and social support in protecting children's self-esteem from the risks posed by courtesy stigma.

Methods: This study took a quantitative, variable-focused approach to examining the relationships between courtesy stigma, self-esteem, attachment and social support, using four self-report measures. Twenty-four children and their parents took part in this investigation.

Results: Attachment to mother and social support were seen to act as resilience variables. However, social support was found to be determined by attachment style. Overall, children reported few relationships outside of the immediate family.

Discussion: These results suggest services to parents with learning disabilities should look to include attachment-based intervention in their work with these families. They also indicate children may benefit from intervention to help build strategies to develop peer relationships

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Introduction

Within British culture, the issue of procreation by people with learning disabilities has long been a controversial subject, the examination of which reveals an unsavoury history.

During the early 1900's, thinking on the subject of disability was heavily influenced by Eugenics theory (Digby, 2005). This led to the view that procreation by people with learning disabilities was a risk to the collective gene pool. McCarthy (1999) documents how society attempted to protect itself from this risk by routinely institutionalising those deemed genetically inferior. Once institutionalised, many were sterilised involuntarily or segregated on the basis of gender, reducing any likelihood of pregnancy (McCarthy, 1999).

This view slowly began to change throughout the mid to late 1900's, due to the pioneering work of academics such as Wolfensberger (1972). Wolfensberger's work became known as the normalisation movement, the principles of which promoted the rights of the learning disabled to a normal life.

Today there is a range of legislation that promotes and protects the parenting rights of people with learning disabilities. This is most recently evident in the government White Paper *Valuing People: A New Strategy for Learning Disability* (Department of Health, 2001).

Sadly, it is nonetheless the case that a significant gap exists between the ideals of the legislation and the reality for many of these families. As Emerson, Malam, Davies and Spencer (2005) report, in this country approximately half of the children born to people with learning disabilities are no longer in their care.

It appears that there are a number of ways in which such people struggle in the parenting role (Feldman, 1994). Notwithstanding the drawbacks of limited cognitive ability, they typically have to contend with low socio-economic status (McGaw and Newman, 2005) and a paucity of services to meet their needs (Tarleton, Ward and

Howarth, 2006). Many are socially isolated (Llewellyn, McConnell, Cant and Westbrook, 1999) and suffer mental health problems at a rate at least three times higher than the general population (Cooper, Smiley, Morrison, Williamson and Allan, 2007).

While these factors no doubt contribute to the high level of child removal into care, there is also evidence to suggest these parents are treated prejudicially by the statutory services. It seems learning disability is often considered a risk factor to safe parenting (Booth, Booth, and McConnell, 2005), despite evidence that intellectual functioning does not relate to parenting ability unless it falls below an Intelligence Quotient (IQ) of 60 (Budd and Greenspan, 1984).

There is a small body of literature on outcomes for the children of parents with learning disabilities. While numerous methodological weaknesses in these studies mean only tentative conclusions can be drawn, there is suggestion that they may be at risk of developmental problems (Feldman, Case, Towns and Betel, 1985; Feldman and Walton Allen, 1997), psychological and social difficulties (Gillberg and Geijer-Karlsson, 1983; McGaw, Shaw and Beckley, 2007), complexities within the parent-child relationship (Kohler and Didier, 1974; O'Neill, 1987) and maltreatment (Booth and Booth, 1997; Ronai, 1997).

There is also indication that children may be vulnerable to 'courtesy stigma' (Goffman, 1963) – a level of discrimination that arises from being aligned with their parents' stigmatised social status (Jahoda, Markova and Cattermole, 1989). Where this occurs, it is likely to pose a risk to a child's self-esteem (Wahl and Harman, 1989); presenting a number of potential risks to their well-being (Emler, 2001).

Courtesy stigma is an understudied area in the literature; only one previous investigation has considered this issue (Perkins, Holburn, Deaux, Flory and Vietze, 2002). No research was found which explored what might protect children against such stigma and promote resilient functioning.

This research was designed to address this gap in the literature. It investigated the role of two key resilience variables; attachment to mother and social support, which

have been shown to support adaptive functioning for children, across a range of undesirable circumstances (Masten, 2001).

This study took a variable-focused, quantitative approach; which allowed for clear definitions of risk and adaptive behaviour. A model was therefore designed which conceptualised courtesy stigma as a threat to a child's well-being, good self-esteem as an adaptive outcome and attachment and social support as resilience variables.

Twenty-four children took part in this research, recruited from nine National Health Service (NHS) trusts and voluntary agencies across England. Children did not have a learning disability themselves and were not subject to child protection plans. All were living at home with their mother, who was their primary care-giver.

Research findings indicated that where a child possessed a good attachment relationship to their mother, their self-esteem was protected against the negative effects of courtesy stigma. Their level of social support was seen to be a by-product of attachment style; those with insecure attachment reporting fewer supportive relationships. Overall, children reported few peer friendships; their support tended to be sought within the family network.

These findings indicate that services to parents with learning disabilities should look to include attachment-based interventions in clinical practice.

This research therefore provides a contribution to the evidence base on resilience in the children of parents with learning disabilities.

Chapter 1: Background

1.1 Definition of learning disability

Over the past century, people with learning disabilities have been labelled idiots, imbeciles, feeble minded, spastics, mentally deficient, mongoloids, mentally retarded and mentally handicapped.

In an attempt to reduce stigmatisation, there has been considerable debate in recent years over the most appropriate name for this group of intellectual disorders. The term 'learning disabilities' is now commonly adopted by health and social services professionals in the United Kingdom. Throughout this thesis, the term 'learning disabilities' or 'learning disability' is used.

Attempts have been made to understand learning disability in terms of a medical diagnosis and a relationship to society as a whole.

Medical model

Three key features have been generally accepted by health professionals in terms of medical diagnosis:

- *Significant impairment in intellectual functioning*
- *Significant impairment in social and adaptive functioning*
- *Onset of the disability should be before the age of 18 years old*

The severity of a learning disability is normally assessed via one of two classification systems: the Diagnostic and Statistical Manual-IV (DSM-IV) (American Psychiatric Association, 1999) and the International and Statistical Classification of Diseases and Related Health Problems (ICD-10) (World Health Organisation, 1992).

Significant impairment in intellectual functioning:

The DSM-IV specifies:

- Profound mental retardation as IQ below 20 or 25

- Severe mental retardation as IQ 20-25 to 35-40

- Moderate mental retardation as IQ 35-40 to 50-55

- Mild mental retardation as IQ 50-55 to approximately 70

Similarly, the ICD-10 classifies:

- Profound mental retardation as IQ below 20-34

- Severe as IQ 20-34

- Moderate as 35-49

- Mild as 50-69

Deficits in intellectual functioning are typically measured using standardised psychometric assessments of IQ. Such assessments are based on a normal distribution model of intelligence in the general population, where the average IQ is 100.

The most frequently used measure of IQ is the Wechsler Adult Intelligence Scale (Wechsler, 1997).

Significant impairment in social and adaptive functioning

Impairments in adaptive and social functioning are more loosely defined. The British Psychological Society (2000, p. 6) describes:

> The individual requires significant assistance to provide for his/her own survival (eating and drinking needs and to keep himself/herself clean, warm and clothed), and/or with his/her social/community adaptation (e.g. social problems solving, and social reasoning).

The ICD-10 and DSM-IV refine the concept of adaptive and social functioning into ten categories:

- Communication
- Self-care
- Home living
- Social and interpersonal skills
- Use of community resources
- Self-direction
- Functional academic skills
- Work
- Leisure
- Health and safety

Both classification systems specify that there must be impairments in at least two of the above criteria for a learning disability to be indicated.

There are a host of assessments for adaptive and social functioning. These are carried out with reference to a host of social and personal factors, such as age, gender, socio-cultural background, religion and community setting (British Psychological Society, 2000).

Onset of the disability should be before the age of 18 years old

DSM-IV requires the onset of learning disability to be before the age of 18 years old. Similarly, ICD-10 states that the disability should develop during the developmental period.

However, in addition to organic learning disabilities, the ICD-10 classification system includes substantial brain injury during childhood as a cause of learning disability.

Summary

The medical model provides a conceptual framework within which a learning disability can be understood and assessed and a person's needs planned for and justified. At its heart it defines a learning disability as the responsibility of the individual, who is restricted by the limitations of their impairment.

However, Swain, French and Cameron (2005) argue that the medical definition of learning disability is reflective of wider western cultural assumptions around the importance of personal autonomy, self-discipline and self-determination.   As Swain *et al.* (2005, p.23) describe:

> Impairment represents a threat to established notions of discipline and normality because it serves to draw attention to uncontrollable nature – to limitations placed upon the ability of humans to shape and organise the world around them as they wish. Impairment signifies disorder, indiscipline, unreliability and, as such, it is perceived as undesirable, something to be cured, overcome or hidden.

As such, Swain *et al.* (2005) levy criticism at the medical model, suggesting its focus is borne of out of a need for individuals to function efficiently in a goal orientated culture.

Social model

By contrast, the social model perceives disability as created by societies that are structured to suit the requirements of the non-disabled population.

From this perspective, disability is something that is done to the individual by society. Swain *et al.* (2005) quote The Union of the Physically Impaired against Segregation (UPIAS), who defined disability as:

> The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical

impairments and thus excludes them from participation in the mainstream of social activities' (UPIAS, 1976, p. 14).

The central point of the social model is to provide a standpoint from which people with learning disabilities can argue for social inclusion and for the same opportunities in life as the non-learning disabled population.

This perspective has provided a basis upon which people with learning disabilities have come together and drawn attention to the barriers they face, through organisations such as CHANGE and People First.

While the social model has provided a valuable framework for the learning disabled population, Thomas (1999) points out that it has been criticised by some as overemphasising discrimination within society, at the expense of acknowledging the significance of actual impairment within the individual.

Definition of learning disability used in this research

Participants in this research were assessed for learning disability on the basis of the DSM-IV definition. This method of assessment was requested by the National Health Service Metropolitan Multi-Centre Ethics Committee (MREC) in January 2005, in order that the study gain ethical approval. The process of MREC ethical approval is discussed further under section 3.4.

Summary

The medical and social models provide alternative theoretical standpoints from which to view disability.

Where the medical model provides a method to categorise and treat different aspects of individual functioning, the social model considers the role society plays in exacerbating the experience of disability and focuses upon helping the individual to live a normal life within mainstream society. Both models contribute to

professionals' understanding of individual need and can be viewed in conjunction with one another.

The current study used the DSM-IV diagnostic criteria to assess learning disability in the participants, in keeping with MREC recommendations.

The next section provides a short history of people with learning disabilities. It illustrates how society's view of the vulnerable has changed over the course of the last two hundred years.

1.2 Historical perspective

The lives of people with learning disabilities

Prior to the Industrial Revolution, people with learning disabilities are thought to have been cared for by their families, rather than by the State. McCarthy (1999) points out that it was not uncommon for a parish to have a 'village idiot' as an accepted member of the community. Many earned a living off the land, or within the home, where they could be supervised by their relatives.

At that time, the learning disabled were only considered a matter of public concern when care broke down. Rushton (2005, p. 60) argues that, in effect, the family was 'at the centre of the state-enforced system of care'.

However, with industrialisation and the rural-urban migration of the 1800's came an emphasis on individual prowess and productivity. Attitudes towards the learning disabled changed and they were increasingly regarded as a burden to the family.

Gradually the responsibility for care moved from the family to the State (Swain, French and Cameron, 2005). This gave rise to the beginnings of institutionalisation for people with learning disabilities.

In 1834, the Poor Law (Digby, 2005) stated that care for the learning disabled should be provided by the workhouses. These soon gave way to the asylums, institutions that housed the mentally unwell, deaf, physically disabled, learning disabled and morally defective (those lacking in moral judgement, be that of a criminal, social or sexual nature).

These institutions became repositories for the unwanted, the uncared for and the dangerous.

Caine, Hatton and Emerson (1998) describe how, during the late 1800's and early 1900's, the number of people with learning disabilities admitted to these asylums steadily rose.

There appear to have been several factors which contributed to this trend:

- The influential medical model began to conceptualise 'idiocy' as an organic disease, recovery from which was not anticipated, but which medication could control. People with learning disabilities were perceived as qualitatively different to the rest of the population and, in some respects, less than human (Caine *et al.,* 1998).

- By the early 1900's the Eugenics philosophy exerted a strong influence over Western society. Caine *et al*. (1998, p. 57) point out its claims that 'social ills, such as poverty, crime and immoral sexual behaviour were caused by people of inferior genetic stock'. The Eugenics movement also argued that such traits were heritable; so those with inferior genes should not be allowed to procreate. The learning disabled woman represented a specific threat to society, as she was thought to be the biological source of the perpetuation of cognitive deficiency (Simmons, 1978).

- The influence of Eugenics led psychologists to develop the concept of intelligence testing. Hendrick (1993) explains how this 'scientific' method enabled the classification of the mentally deficient at an early age: increasing numbers of children were placed in institutions.

McCarthy (1999) points out that, during the early 1900's, many learning disabled women were sterilised in the United Kingdom. In America, such practices were taken even further. Digby (2005) reports that between 1900 and 1940, sixteen different states within America passed a law for the mandatory sterilisation of those deemed biologically inferior.

At the end of the Second World War, public opinion turned against involuntary sterilisation, in both the United Kingdom and the United States.

This was in no small part influenced by the atrocities of the Nazi Regime in Germany, which cast a dark shadow over the Eugenics movement; one that ultimately

contributed to a paradigm shift in society's perception of the vulnerable. In the United Kingdom, involuntary sterilisation subsequently became a matter for judicial review.

This shift in public opinion coincided with the launch of the NHS in 1948. The care of people with learning disabilities was transferred to the NHS, who began to be seen as patients with health problems, rather than incurable souls that required management. The asylums became long-stay hospitals.

This shift was quickly modified further by the pioneering work of social scientists such as Goffman (1961). Goffman's work on the stigmatising and handicapping effects of institutions contributed to the view that the long-stay hospitals were not the answer. Indeed, they quickly came to be seen as a contributory factor in discrimination towards the learning disabled (Digby, 2005).

Goffman's observations were reflected in a number of scandals that came to light in the long-stay hospitals at that time: most notably, the Ely Hospital in Cardiff in 1969 and South Ockendon Hospital in London in 1974. Investigations into practice in these hospitals revealed widespread institutional abuse of people with learning disabilities by the staff charged with their care (Digby, 2005).

Legislation of the period reflected the changing mood. The White Paper *Better Services for the Mentally Handicapped* (Department of Health and Social Security, 1971) stated that long-stay hospital accommodation should be halved within fifteen years. As an alternative, it requested that local authorities establish parallel community-based services for the learning disabled.

There followed a large scale review of services across the United Kingdom over the course of the 1970's (Leighton, 1988; Lowe, 1993), heavily influenced by the work of academics such as Wolfensberger (1972).

Much of Wolfensberger's (1972) work was focused on the ideologies, structures and planning patterns of human service systems, particularly concerning people with learning disabilities. He aimed to address their social devaluation by contemporary

society and argued that they be afforded the same opportunities in life as the mainstream population.

Wolfensberger's work became the cornerstone of the 'normalisation movement'. Thomas and Woods (2006) cite Wolfensberger (1977, p.471) in describing the principle of normalisation as 'the utilization of culturally valued means in order to establish and/or maintain personal behaviours, experiences and characteristics that are culturally normative or valued'.

Normalisation exerted considerable influence over the philosophy and structure of service provision to people with learning disabilities, from the 1970's onwards.

The 1980's brought an increasing focus on community-based care in the United Kingdom. The *Care in the Community Initiative* (Department of Health and Social Security, 1981) furthered the 1971 requests of *Better Services for the Mentally Handicapped*. It required that resources be transferred from the NHS long-stay hospitals to local authorities, insisting that residents move into community settings.

The government White Paper *Valuing People* (Department of Health, 2001) has further supported the rights of people with learning disabilities to the same life opportunities as the rest of the population: it states that statutory services have a responsibility to consider appropriate housing, leisure opportunities, day centres, health care, education and (where possible) employment for people with learning disabilities. It also advocates the right to have children, and a normal family life.

Despite these steps towards inclusion in mainstream society, *Valuing People* (Department of Health, 2001) points out that people with learning disabilities remain amongst the poor, most socially excluded within Britain today. As such, those who chose to become parents hold a significantly disadvantaged social status.

The next section turns to the current legislation in the United Kingdom, which governs the nature of service provision to parents with learning disabilities. However, it seems there are a number of complex difficulties which compromise the quality of services parents receive.

1.3 Government legislation and practice guidance on parents with learning disabilities

Legislation

Over the last twenty years a significant number of government acts have been passed that have upheld the rights of people with learning disabilities to a normal life and to enjoy the same opportunities as the rest of society. These have included the rights to vote, marry and have children.

While not an exhaustive list, the following legislation currently governs service provision to parents with learning disabilities in the United Kingdom:

- The *Children Act* (Department for Education and Skills, 1989) states that the children of parents with learning disabilities should not be seen as at-risk simply because of their parents' cognitive limitations. It suggests that children's needs are normally best met by their own family – therefore, parents should receive statutory support to aid them in their parenting role.

- *The National Health Service and Community Care Act* (Office of Public Sector Information, 1990). Under this act, authorities are required to carry out assessment of the practical needs of people who are having difficulty living independently, if they appear to be in need of statutory services.

- The *Disability Discrimination Act* (Office of Public Sector Information, 1995) makes it illegal for any service provider to discriminate against someone on the grounds of disability. Furthermore, it supports the rights of the learning disabled community to access mainstream public services in the same way that non-disabled people can, by requiring service providers to make 'reasonable adjustments' to the way they deliver their services so that disabled people can use them. An example of a reasonable adjustment may be the inclusion of

disability awareness training for members of staff, or the provisions of ramps and wheelchair access to premises.

- The *Human Rights Act* (Office of Public Sector Information, 1998) makes it clear that everyone has the right to marry and/or form a civil partnership and start a family. Furthermore, it states that everyone has the right to a fair hearing, which includes court cases as well as case conferences and other meetings arranged by adult and children's services departments. If a parent has learning disabilities, for example, local authorities must make sure that they are able to participate fully and have information explained to them in a way that is appropriate for their learning needs. This Act also states everyone has the right to respect for private and family life. This means a local authority can only interfere with family life if it is necessary for the safety of others (such as the need to protect a child).

- The *Health and Social Care Act* (Office of Public Sector Information, 2001) enables parents to access direct payments through the 1989 *Children's Act.* These financial benefits can be used by people with learning disabilities to aid them in their parenting role.

- The government White Paper *Valuing People: A New Strategy for Learning Disability* (Department of Health, 2001) represented the first re-think of services to people with learning disabilities in over thirty years. With respect to parenting, it states that the NHS should work nationwide with social services to support parents with learning disabilities and their children.

- *Fair Access to Care Services* (Department of Health, 2003) outlines the eligibility criteria for adult social services and states that local authorities have a responsibility to support the needs of adults in a parenting role. Social services are required to consider such needs under the *Children Act* (Department for Education and Skills, 1989), the *Framework for the Assessment of Children in Need and their Families* (Department of Health, 2000) and the government Green Paper *Every Child Matters* (Department for Education and Skills, 2003).

- *Improving the Life Chances of Disabled People* (Prime Ministers Strategy Unit, 2005) sets out a programme which aims to empower disabled people to help themselves via inclusion in mainstream services.

In summary therefore, the last two decades have seen the arrival of a range of legislation which has upheld the rights of people with learning disabilities to have children and to be given appropriate financial and practical aid to support them in doing so. However, research into services for parents with learning disabilities unfortunately indicates a number of entrenched difficulties in delivering the aims of this legislation.

Practice guidance

In the last ten years, several reports into services for people with learning disabilities have been commissioned by the Social Services Inspectorate, the National Health Service and public research bodies such as the Joseph Rowntree Foundation.

Enquiries carried out by the Department of Health (*Good Practice Guidance on Working with a Parent With Learning Disabilities*, 2007), Goodinge (2000), Morris (2003), Olsen and Tyres (2004), Tarleton *et al.* (2006) and Wates (2002) have investigated the quality of services provided across the United Kingdom. They show remarkable consensus on a number of issues:

- The eligibility criteria to the nationwide Community Learning Disability Teams (CLDT) are too restrictive, leaving the CLDTs unable to appropriately respond to the needs of parents with learning disabilities.

- Neither child services nor the CLDTs have appropriately qualified staff with the necessary skills to undertake parenting assessments or to provide parenting courses. Indeed, in a nationwide survey, Tarleton *et al*. (2006) found less than half the staff they interviewed had any kind of training in parents with learning disabilities.

- The parenting needs of disabled adults frequently fall between adult community care provision and children's services. While children's services tend to focus on assessing child needs and welfare, including child protection issues; adult services tend to focus only on the provision of services to adults with learning disabilities. Consequently, professional agendas can be divergent and even sometimes contradictory.

- Support for these parents is often crisis-driven, although it would be most effectively delivered on a long-term and sustainable basis.

- Child and adult services should pool budgets in order to make provision for parents with learning disabilities and their children.

- A national protocol should be developed that sets out how child and adult services should work together.

It seems that there are a number of difficulties in service delivery, which no doubt influence the quality of support available for parents. In addition there appear to be a number of other factors which create barriers to support.

Barriers to providing effective support

The Social Care Institute for Excellence (SCIE) points out that funding to such services is often limited, impacting on the quality and quantity of support available to meet parents needs (*Report 6: Managing risks and minimising mistakes in services to children and families,* SCIE, 2005).

Services are required to perform a difficult role with these families - monitoring risk while at the same time aiming to facilitate effective parenting. In doing so, professionals have to balance legislation that protects the rights of parents alongside that which protects the rights of children (*Good Practice Guidance on Working with Parents with a Learning Disability*: Department of Health, 2007). Booth (2000) highlights the conflicting responsibilities of social workers in such circumstances and the tension they often have to negotiate between policing and enabling vulnerable

families. As Harris (1990) observes, such families are frequently required to seek help from the very professionals who have the main statutory responsibility for child protection.

Cleaver and Nicholson (2008) suggest this often leads to difficulties in the way parents perceive services; making it less likely they will approach children's social care for support. The document *Good Practice Guidance on Working with Parents with a Learning Disability* (Department of Health, 2007) draws attention to the fact that parents with learning disabilities often mistrust professionals, resulting in a lack of engagement with child and family services for fear their child will be removed. This ultimately results in those services becoming even more concerned about their parenting capacity, creating a vicious circle between the parent's wishes and the professional's responsibilities to protect the welfare of the child.

Where a child is considered too vulnerable to remain with their parents and removed into care, social workers are sometimes faced with further complicating factors. Tarleton *et al.* (2006) report that some social workers feel pressurised by the implications of the *Adoption and Children Act* (Office of Public Sector Information, 2006). This legislation requires them to minimise the amount of time a child stays in the care proceedings process, and there is an increased impetus to move quickly through to adoption (Tarleton *et al*., 2006).

These issues are compounded by the reactive nature of service provision. Many parents with learning disabilities often only come to the attention of services once crisis point has been reached (Goodinge, 2000). This increases anxiety among professionals and makes it more likely that social workers will adopt what the Social Services Inspectorate has termed an 'over zealous' approach to risk (Goodinge, 2000).

A culture of blame also presides in children's services (*Report 6: Managing risks and minimising mistakes in services to children and families,* SCIE, 2005), increasing the likelihood that individual professionals will look to rule out any risk in vulnerable cases. The pressure upon child social workers is exacerbated by every child abuse scandal reported in the press, most recently in the sacking of Sharon Shoesmith, director of children's social services in Haringey, in connection with the death of

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'baby P' at the hands of his mother and her boyfriend (The Guardian, 2008 December 1).

Brown (1994) argues that behind a facade of political correctness, society holds negative stereotypes about the ability of people with learning disabilities to parent. He suggests that these stereotypes influence the structure of service provision, arguing that a lack of available support, combined with the punitive process of the child care system, results in a mass denial of parenting rights among the learning disabled population.

These stereotypes permeate society at the most fundamental levels. Within health, social services and the judiciary system, a presumption of incompetence exists with regards to parents with learning disabilities. These presumptions are often quietly held, but nonetheless amount to a belief that these parents' cognitive and social limitations make them unsafe parents (Booth, 2000).

Such prejudices may even influence the nature of parenting assessments. Booth (2000) draws attention to the deficiency perspective within such assessments, which have an emphasis on identifying what is wrong without equally taking on board people's strengths and how these may be built on. Consequently, professionals have a tendency to focus on evidence that supports their negative presumptions, influencing outcomes for the family (Booth, 2000).

Evidence for Brown's (1994) and Booth's (2000) assertions are seen in the study by Tarleton *et al.* (2006). They found that staff without specialist knowledge often held negative views about learning disabilities and parenting. Professionals gave mixed messages as to what constituted 'good enough' care-giving, leaving parents unsure of what they were expected to do. Some staff ruled out any risk to the child and set 'impossibly high standards' for parents to meet – at a much higher level than those applied to non-disabled people. In effect, negative stereotypes held by individual professionals were seen to influence efforts made to help the family (Tarleton *et al.,* 2006).

Summary

While legislation fully supports the parenting rights of people with learning disabilities, key reports over the past decade have highlighted a number of issues in terms of service delivery.

The CLDT eligibility criteria is criticised as restrictive, leaving parents without the services they require. Staff lack appropriate skills to address parenting needs and there is a deficiency in co-ordinated planning between child and adult services. This is exacerbated by the lack of national protocol setting out how these agencies should work together.

There are additional factors which impede effective intervention for these parents. They are required to seek support from the very professionals who have responsibility for child protection, which leaves them mistrustful and less likely to ask for help. This issue is exacerbated by the blame culture within which social workers are required to make decisions about vulnerable children; a culture which may indeed compromise professionals' ability to provide enabling interventions to these families.

A greater, more pervasive, barrier to support is also identified in the prejudicial stereotypes held by both individual professionals as well as the statutory services as a whole. Such stereotypes inevitably influence the quality of support offered to parents at the most fundamental level.

While service-related issues are an important consideration with respect to parenting in this population, there appear to be a number of additional factors that characterise care-giving competence. These are reviewed in the following section.

1.4 Parenting provided by people with learning disabilities

In addition to a paucity of services to meet their needs (Tarleton *et al*., 2006), parents with learning disabilities typically have to manage the effects of low socio-economic status, poor housing, a lack of education, unemployment and limited life opportunities (McGaw and Newman, 2005). Webster-Stratton (1998) suggests that many of these factors are related to negative child and parenting outcomes. Consequently, these parents share similar problems with other vulnerable parents in society who may also come to the attention of the child protection services.

However, Feldman and Walton-Allen (1997) suggest that while impoverishment is a significant issue in determining parental competency, it does not account for the range or degree of difficulties experienced by parents with learning disabilities.

There are a number of specific issues that appear to relate to care-giving competence in this population: intellectual functioning when it falls below IQ of 60 (Budd and Greenspan, 1984), parenting skills deficits (Feldman 1994; Hur, 1997), lack of social support (Llewellyn and McConnell, 2002) and mental health problems (McGaw *et al*., 2007) are all key factors. The number of children there are to care for in the family and a child's characteristics may also play a role in parenting ability, although there has been limited investigation into these issues to date (Dowdney and Skuse, 1993; McGaw and Newman, 2005). There is evidence to suggest parents may be at increased risk of neglecting their child, although child abuse appears to be more likely to occur at the hands of another adult known to the mother (Tymchuck and Andron, 1990). However, many of these studies demonstrate significant weaknesses in design, limiting the generalisability of findings.

Intellectual Functioning

That a low IQ relates to a lack of parenting ability may seem to be a logical assumption. However, there is general agreement in the literature that IQ alone does not relate in any systematic way to parenting competence until it falls below 55-60 (Budd and Greenspan, 1984).

McGaw and Newman (2005) point out that the majority of parents fall in the mild to borderline IQ range (IQ 60-70). Despite this, successive increments within the IQ range are not associated with better parenting practice, so IQ levels alone are not considered a sufficient explanation for either strong or weak parenting skills.

This may be because formal assessments of IQ do not measure cognitive capacities that are likely to have a direct influence upon parenting skills. Indeed, Budd and Greenspan (1984) report that day-to-day living skills, such as the ability to plan and organise household chores, to manage relationships with schools and services, to understand and anticipate social events and to assess the consequences of personal actions, are more important determinants of 'good enough' parenting than IQ.

Parenting skills

There has been a significant level of enquiry into parenting skills in this population (Feldman, 1994; Hur, 1997). This literature suggests that parents with learning disabilities lack a basic knowledge of child health and safety (Tymchuck, Andron and Hagelstein, 1992; Feldman, 2004), decision making in child-rearing (Tymchuk, Yokota and Rahbar, 1990) and proper nutrition (Feldman, Garrick and Case, 1997). They also struggle to understand basic child development information (Feldman, Case, Towns and Betel, 1985) and to provide nurturing interactions with their children (Feldman, Sparkes and Case, 1993; Slater, 1986; Tymchuk and Andron, 1992).

However, weaknesses in research designs have resulted in no clear definition of adequate parenting, varying methods of assessment, recruitment bias, inconsistent definitions of learning disability and small sample sizes. As such it is difficult to clarify the extent of skills deficits in this population.

The lack of concrete definition of 'adequate parenting' is a fundamental difficulty for investigators in this area (Tymchuck and Feldman, 1991). Furthermore, the definition of 'parenting skills' differs; some focus on issues such as parent-child interaction (Tymchuck and Andron, 1992), where others address parental knowledge of safety in the home (Tymchuck *et al*., 1992), making it difficult to draw conclusions about parenting abilities.

Studies also vary in terms of their assessment of parenting skills as well as their measure of outcome. Many have used observation of parenting (e.g. Crittenden and Bonvillian, 1984), while some have used a combination of observation and interview (e.g. Feldman *et al*., 1986). Few have used standardised assessments such as the HOME inventory (Caldwell and Bradley, 1984). Unfortunately standardised assessments of parenting are limited for this client group; McGaw (2006) points out that no one assessment tool as yet covers the whole range of child care skills and can accurately predict overall parenting abilities.

Research in this area has defined learning disability in different ways. Some include parents with IQ in the borderline range (IQ 70-80) as well as parents with similar socio-economic circumstances but no diagnosis of learning disability (Feldman *et al*., 1992). Others such as Tymchuck *et al.* (1992) have focused on mothers with more significant disabilities (IQ 50-69). This makes comparisons between studies problematic, as mothers with IQ's in the borderline range may not face the same level of difficulty as those whose IQ falls below 60.

Many interventions reported are with parents who had reached crisis point. Consequently, they represent a 'skewed sample' and their skills deficits may not be representative of parents with learning disabilities as a whole (Tymchuck, 1992a).

The majority of studies have used single-subject, multiple-baseline design (Feldman, 1994; Hur, 1997), although fundamental flaws in methodologies have effected outcomes. This approach has been used to investigate child-care skills (Feldman *et al.*, 1992), parental decision making (Tymchuck *et al*., 1988), home safety (Tymchuck, Hamada, Andron and Anderson, 1990) and parent-child interaction (Tymchuck and Andron, 1988).

Single-subject methodology requires baseline recording of target parenting skills, which are then compared against outcome recordings. Yet, in a review of the effectiveness of parent training programs, Feldman (1994) found a lack of baseline recording undermined the integrity of research findings in nearly half of the studies he reviewed. Consequently, the extent of parents' skills deficits were not clear.

A small number of studies have used a between-groups methodology (Tymchuck *et al.,* 1990; Tymchuck and Andron, 1992). The advantage is that it allows for comparisons, which provide valuable information about differences in parenting skills between parents with and without a learning disability (Hur, 1997). However, the numbers of participants are often small, reducing statistical validity. Furthermore, control groups should be matched on crucial demographic information, such as parental history, mental health, socio-economic status, child age and development, which is often difficult to achieve.

Overall, both single-subject and between-groups designs have tended to use small numbers of participants, ranging from n = 3 (Tymchuck *et al.,* 1992) to n = 33 (Feldman, 2004). Consequently, the statistical generalisability of findings is limited, although this is a common dilemma for researchers in this area (Hur, 1997).

Despite methodological issues with study designs, the literature broadly suggests that parents may struggle to provide basic care for their child (*Best Practice Guidance on Working with a Parent with a Learning Disability*: Department of Health, 2007).

Mental health problems

Borthwick-Duffy (1994), Deb, Thomas and Bright (2001) and Iverson and Fox (1989) report the prevalence of mental health problems in the learning disabled population to be two or three times higher than in the normal adult population. Yet to date there has been little investigation into the prevalence of mental health problems specifically among parents with learning disabilities (McGaw, Shaw and Beckley, 2007). This is despite the fact that parental mental health issues are frequently cited as contributory factors when a child is removed into care (Booth, Booth and McConnell, 2005).

A recent study by McGaw *et al.* (2007) provides some evidence on the incidence of psychopathology in parents with learning disabilities in the United Kingdom. They investigated the prevalence of childhood abuse and psychopathology in forty-nine mothers and fathers who had been referred to a specialist learning disabilities service. The average IQ of the parents was 72.8, although the study does not report how this was assessed or how adaptive behaviour skills were evaluated. Independent measures were used to assess parental histories of childhood abuse and adult psychopathology.

Overall, 79.6% of the sample reported abuse or neglect of some form during their own childhood, with 51% citing multiple abuse/neglect categories. Females in the sample reported more severe abuse compared with males.

They found that 45% of parents demonstrated some form of psychopathology. The most frequently reported mental health problems were depression (33%) and anxiety (20%). Psychosis was identified in 10% of the sample and obsessive-compulsive disorders in 12%. Hypomania/mania was reported for 4% of participants. Females were significantly more likely to report psychopathology than males.

The data was cross-tabulated between categories of childhood abuse and psychopathology. A weak association was found between childhood trauma and adult psychopathology ($p > 0.05$), except in cases where childhood sexual abuse had been reported ($p < 0.05$).

McGaw *et al.* (2007) also compared their research findings with the prevalence of psychopathology identified in the general population of parents. They point out 45% of their sample indicated mental health problems, where studies in the general population have indicated a 10%-23% incidence rate (Gustafsson, 2003; Lewis and Creighton, 1999).

The McGaw *et al.* (2007) findings suggest that parents with learning disabilities are significantly more likely to experience mental health difficulties than the general population of parents.

However, participants in this study were drawn from a service to which they were known due to problems with child-care, so again the issue of whether they can be seen as representative of parents with learning disabilities as a whole is raised. No comparison group was used; the inclusion of which would have further clarified findings. Lastly, parents were assessed for childhood abuse using a self-report inventory. People with learning disabilities often struggle with memory function, comprehension and processing ability, so using a self-report measure as the only source of information to capture early life experience may not have provided reliable data.

It appears that, despite evidence that people with learning disabilities are at greater risk of mental health problems than the majority of the population, there has been limited investigation into its prevalence, specifically among parents. The study by McGaw *et al*. (2007) marks the beginning of this enquiry. Although methodological flaws are noted in this research, it seems the rate of psychopathology may be significantly higher in parents with learning disabilities than in the mainstream population.

Number of children in the family

Very little research has considered the relationship between the number of children a parent has to care for and parenting competence. However, Dowdney and Skuse (1993) report a study by Accardo and Whitman (1990a), which found that the likelihood of a child being abused or neglected tended to increase, and that day-to-day living skills and quality of parental care tended to decrease, the more children there were in the family.

While no research has established whether there is a maximum family size above which risk increases, it has been posited that parenting three or more children is likely to be 'substantially more stressful and demanding than parenting one or two' (Dowdney and Skuse, 1993, p. 35).

Child characteristics that stretch capacity

The individual temperament of a child and the effect this may have on parenting ability is a factor that has been widely considered in the general population (e.g. Porter *et al.*, 2005). Yet, as McGaw and Newman (2005) point out, there has been little investigation to date into this issue for with the children of parents with learning disabilities.

However, research would seem to suggest these children are at increased risk of developmental delay (Feldman *et al.,* 1985) and learning disabilities (Dowdney and Skuse, 1993). The greater needs children may have in such circumstances are likely to place extra demands on a parent and compromise care-giving where it is already fragile (Dowdney and Skuse, 1993).

Child abuse

Research into the prevalence of child abuse committed by parents with learning disabilities draws contradictory conclusions. Some studies report high levels of abuse, while others indicate the opposite.

Schilling, Shinke, Blythe and Barth (1982) carried out a review of the literature on learning disability and child maltreatment. They reviewed fourteen studies, of which all but one found parents with learning disabilities to be at risk of abusing their children. However, these studies were hampered by small sample size, lack of matched control groups and inconsistent definitions of maltreatment. Studies also varied in their definition of learning disability, with one including parents with IQ in the low average range.

Although Schilling *et al.* (1982) acknowledge methodological flaws within the studies, they conclude that 'the preponderance of evidence points toward increased risk of maltreatment for children reared by mentally retarded parents' (Schilling *et al.,* 1982, p.206).

Conversely, Tymchuck and Andron (1990) carried out a study with thirty-three learning disabled mothers who were admitted to a parenting project in California. They found fifteen of the mothers were categorised as neglectful, but only two as abusing, suggesting their study provides evidence that 'abuse is not an inherent characteristic' of mothers with learning disabilities.

In fact, they identified that where abuse did occur, the perpetrator was most frequently another adult associated with the mother, such as a partner or friend. Although in cases where the mother committed purposeful child abuse, they found that there was a strong likelihood of future abuse. Furthermore, such mothers were less likely to benefit from the intervention of services, being either reluctant to learn or to maintain parenting skills taught.

However, all of the parents included in this study were drawn from a service that aimed to teach 'optimal parenting skills' within the community and the mothers in question were not considered to be particularly at risk of harming their child. Consequently, it is difficult to draw firm conclusions from their findings.

The research suggests where a child is at risk of abuse, outcomes may be influenced by the support of another, non-disabled, adult in the home:

Seagull and Scheurer (1986) carried out a study with sixty-four children who had been referred to a specialist assessment centre due to concerns of abuse. As a result of the maltreatment, only eleven children were allowed to remain with their learning disabled parents: six were put forward for voluntarily for adoption and the courts relinquished the rights of the parents in the rest of the cases. The distinguishing characteristic of families in which children remained with their parents was the presence of another adult to give daily support. In some cases this was the husband of a mother with learning disabilities, in other cases grandparents or extended family members were actively involved in child-care.

It is not clear therefore whether these children are at greater risk of abuse. However, it seems that where abuse does occur, it is normally by another adult known to the mother (Tymchuck and Andron, 1990). Support from family or a partner has been

found to have a moderating effect on the risks of maltreatment (Seagull and Scheurer, 1986).

Child neglect

Maternal IQ of below 60 is understood to be predictive of neglect (Dowdney and Skuse, 1993). However, there is evidence to suggest that, even above this IQ level, children are at risk of neglect from their parents (Tymchuck, 1992).
McGaw and Newman (2005) report that while maternal learning disability is identified as a risk factor for medical, cognitive and emotional problems in children, the primary cause of child neglect appears to be as a result of a lack of parental education combined with a lack of support services.

To McGaw and Newman (2005, p.20) 'neglect appears to occur as a result of acts of omission rather than commission'. It seems that a parent simply failing to understand how to carry out basic care-giving tasks puts these children at risk of neglect.

However, neglect can also arise out of a failure to meet a child's needs for reasons other than lack of knowledge or support. For example, Schilling and Schinke (1984) identified that children with disabilities themselves are at particular risk. Those with special needs may require frequent medical appointments, particular diets and close supervision. Yet even when a mother understands that these issues should be addressed, the organisation and execution of such tasks may prove too complex to manage (James, 2004).

Lack of social support

Parents with learning disabilities are considered to be amongst the most socially isolated in our community (McGaw and Newman, 2005).

Much of the research that has investigated social support systems for this population has been conducted by Llewellyn and colleagues in Australia (e.g. Llewellyn and McConnell, 2002; Llewellyn *et al.,* 1999), although a small number of studies have

also been carried out in the United Kingdom (Sternfert-Kroese, Hussein, Clifford and Ahmed, 2002; McGaw, Ball and Clark, 2002).

Llewellyn and McConnell (2002) interviewed seventy mothers with learning disabilities to examine the nature of their support systems. Mothers were defined as having a learning disability using the social systems perspective (Mercer, 1973) – that is, they were considered by service providers to be learning disabled. Participants were recruited via social services departments; those not known to (or no longer receiving treatment from) services were not included.

Mothers living alone tended to have service-centred support networks; those with a partner had more family-centred networks with relatively dispersed family ties; and those living in a parent household tended to have local, family-centred networks. Interestingly, regardless of living arrangements, they identified that mothers were not likely to have friends or support from neighbours. This is of particular concern, given the role of friendship in a person's quality of life and social integration (House, Umberson and Landis, 1988; Newton, Horner, Ard, LeBaron and Sappington, 1994).

While Llewellyn and McConnell (2002) provide a valuable insight into parent support networks, it is important to note that their research was carried out at one fixed point. Mothers' networks may alter – when their child starts school, for example, or when they find employment. Support networks therefore cannot be seen as fixed entities. All the mothers in their study were also known to services, which raises questions about the extent to which they reflected the support networks of mothers with learning disabilities as a population. Lastly, the social systems definition of learning disability that Llewellyn and McConnell (2002) used to define their population may have allowed for the inclusion of mothers whose IQ was in the borderline or low average IQ range (IQ 70-89). Consequently, the degree to which their sample reflected the actual experience of mothers whose IQ fell in the learning disabilities range is not clear.

In the United Kingdom, Sternfert-Kroese *et al.* (2002) considered the effectiveness of mothers' social support networks. They investigated the number of social contacts relevant to the parenting role, the helpfulness of these contacts and the relationship

between support received, self-esteem and assertiveness. The participants included seventeen mothers with mild to moderate learning disabilities, although the method by which learning disability was assessed was not reported. Mothers were assessed for self-esteem, assertiveness and well-being using standardised measures. They were interviewed about their support networks using a semi-structured format.

They found that psychological well-being was positively correlated with the size of mother's social support network. How recently the support had been received was positively correlated with self-esteem. Self-esteem negatively correlated with reported burdens of parenthood. Consequently, they conclude that social support affects parenting indirectly, via its effects on psychological well-being.

Overall, mothers in the study reported fewer supports (an average of five) than found among parents without learning disabilities, where an average of thirteen has been reported (Levitt, Weber and Clark, 1986). In fact, only one-third of the mothers reported any friends at all; the majority of support was provided by family-centred networks. However, the sample size was small in this study and not randomly selected. As such the generalisation of findings is limited.

Another British based study on social support for these mothers was carried out by McGaw *et al*. (2002). They investigated the effects of a group intervention intended to raise social awareness and enhance interpersonal communications and listening in relationships. Parents included in the study had an IQ between 53 and 85, as measured by the Wechsler Adult Intelligence Scale (Wechsler, 1997). The study took a between-groups design: twelve parents participated in the group intervention and ten parents (who also had learning disabilities) did not. Baseline measures of self-concept, parent-child adjustment and parents' perceptions of their child's behaviour were recorded using standardised assessments.

Self-esteem was found to improve for parents who participated in the group program and gains were maintained at follow-up twenty-seven weeks later. However, improvement in self-esteem was not seen to impact on a parent's perceptions of their children. Significantly, single parents were found to be more vulnerable to negative self-concept than parents in a relationship. It was concluded that group intervention

can improve the self-concept of parents with learning disabilities, which is particularly relevant for service providers when planning effective intervention. McGaw *et al.'s* (2002) study is helpful in highlighting the benefits of group training in terms of social support. However, as with previous studies, the sample included mothers in the borderline IQ range and the sample size was small, although the use of standardised measures and a control group increased the reliability and validity of the findings.

Despite weaknesses in study designs, research into support networks suggests that mothers with learning disabilities are isolated within their communities; support is often derived from services. Even where a mother does have a family centred network, she is less likely than other mothers to have friends to rely upon.

Social support is a critical factor for these mothers: it has been shown to enhance self-esteem, which benefits the parenting role. Indeed, absence of suitable familial and social support for a mother is actually predictive of parenting breakdown (Tymchuk, 1992).

Rates of child removal into care

There are varying estimates of the percentage of children removed from their learning disabled parents.

Booth *et al.* (2005) provide an overview of the international research on this issue, which indicates the prevalence rate to be between 30% and 50% (Accardo and Whitman, 1990; Faureholm, 1996; McConnell and Llewellyn, 1998; Mirfin-Veitch, Bray, Williams, Clarkson & Belton, 1999; Morch, Jens & Andersgard, 1997; New York State Commission on Quality of Care for the Mentally Disabled, 1993; Nicholson, 1997; Pixa-Kettner, 1998; Van Hove and en Wellens, 1995).

The most recent study in Britain found 48% of parents interviewed were not looking after their own children (Emerson *et al.,* 2005). However, as Dowdney and Skuse (1983) point out, removal into care is not necessarily a reliable indicator of parenting

failure within this population. Other factors (such as the prejudicial attitudes of professionals, services and the courts, as well as a lack of support services) can also influence the prevalence of child removal (Booth, 2000).

In a recent study the records of the Family Proceedings Court and the County Court in Leeds and Sheffield in the year 2000 were reviewed. In total, four hundred and thirty-seven care applications were identified, of which sixty-six were found to involve at least one parent with a learning disability. A further twenty-one applications referred to one or both parents having a borderline learning disability (Booth *et al.*, 2005).

The children of parents with learning disabilities were represented in more than one in six of all local authority care applications. On this basis, 'parents with learning disabilities and their children feature in care applications a minimum of fifteen times and, more realistically, up to fifty times more often than would be predicated on the basis of their numbers in the population' (Booth *et al.*, 2005, p. 14).

Most of the children were brought to court for reasons of neglect. However, social services case notes revealed that problems giving rise to professionals' concerns were directly related to the mothers' learning disability. For example, there were concerns about mothers' lack of insight and skills alongside their insufficient ability to understand change. Although the disability had been identified as the risk factor, Booth *et al*. (2005) found little evidence to suggest parents were provided with support services to help them compensate for their disadvantages.

The study provides evidence that parents with learning disabilities are over-represented in care proceedings and suggests '…these stark facts unavoidably raise questions about discriminatory treatment' (Booth *et al*., 2005, p.15).

While it appears approximately half of these children are involved within the child care system at any one point in time; this figure may not be seen as simply representative of parenting failure.

Emotional and financial costs of child removal into care

Where children are removed from their parents and unable to return, adoption is often seen as a route to a stable family life (Selwyn, Frazer and Quinton, 2006).

Despite the fact that the *Adoption and Children Act* (Office of Public Sector Information, 2006) states that permanent placements should be found as quickly as possible, a brief review of the literature illustrates that identifying such placements can be complex and fraught with instability. Consequences for the child can be catastrophic.

For example, Selwyn *et al.* (2006) reviewed the outcomes of one hundred and thirty older, looked-after children who had all been freed for adoption. They found 26% had spent time in long-term foster care and 12% were not in a stable placement. Some had experienced five or more placement breakdowns.

Delays in finding placements were sometimes due to a lack of clear planning, which was often exacerbated by poor social work assessment. Staff vacancies, sickness and delays were common. Problems were also caused by families who were hard to support, particularly if they moved home without notifying the local authority of a new address. Further complications arose where children had challenging behaviour and/or disabilities that made them hard to place with adoptive families.

The emotional impact of these delays was significant. Selwyn (2006) reviewed case files, which contained records from concerned teachers and foster carers. One child wrote in their schoolbook 'What will happen to me?' Another was recorded as accosting strangers and knocking on doors asking 'Will you be my mummy?' A further child was reported as putting his fingers down his throat and saying, 'So I will die'.

The cost of delay is financial as well as emotional. The average cost per child from entry into care to the time of the 'best interests' decision, using 2002 prices, was £39,469. Those children who were difficult to place were typically costing £3,000 per week per child, or approximately £144,000 per year. On average, these more

complex cases were - by the time they were permanently placed - costing social services departments approximately half a million pounds (Selwyn *et al.*, 2006).

Research has shown that children who spend time in care and are looked after by high numbers of staff are at increased risk of poor developmental outcomes. In reviewing literature on the impact of institutional care, Johnson, Browne and Hamilton-Giachritsis (2006) found evidence to suggest it may negatively effect children in terms of their brain growth, the ability to form a positive attachment to others, social behaviour and cognitive development.

Consequently, it seems that not all children who are removed from their learning disabled parents will receive significantly better care-giving - particularly in the short term - while placements are found. Their longer term outcomes may also be effected, in cases where permanent carers can not be found. As such, the impact of the care pathway can be disastrous emotionally for the child as well as financially for statutory services.

Summary

While parental IQ below 60 is predictive of parenting failure, IQ alone is not considered to be a sufficient indicator of parenting ability (Budd and Greenspan, 1984).

Other issues seem to exert a stronger influence over care-giving competence - such as parenting skills, mental health problems, the number of children there are in the family and level of parental social support (Dowdney and Skuse, 1993; Feldman, 1994; Llewellyn and McConnell, 2002; McGaw *et al.,* 2007). It also seems that the children of parents with learning disabilities may be at risk of abuse, most commonly from another adult known to the mother rather than from the parent themselves (Tymchuck and Andron, 1990).

However, a number of methodological weaknesses are seen in the literature on parenting by people with learning disabilities. Many studies draw their samples from

services, to which parents were known precisely because of their parenting difficulties. This creates a bias in recruitment and means those included may not be representative of the population of parents with learning disabilities as a whole. Different studies also vary in their definition of learning disability, with some including mothers in the borderline range or without an assessment of IQ at all. Much of the research in the area has used small sample sizes, reducing the reliability of findings. There are few studies of comparative design, where parents with learning disabilities have been matched with parents from the same socio-economic status. Consequently, not all of the research can be seen as conclusive evidence with regards to parenting qualities or abilities in this population.

Parents with learning disabilities are particularly at risk of neglecting their children (McGaw and Newman, 2005). Neglect is most commonly due to omission of care, rather than abusive intention. Nonetheless, it is the most common reason for child removal into care in this population, the prevalence rate of which has been estimated to be approximately 50% (Booth *et al.*, 2005).

Yet it appears that, for some children, removal into care will not immediately improve their situation (Selwyn *et al.*, 2006). Delays in finding placements have been found to increase child distress, while incurring substantial financial costs to social services (Selwyn *et al.*, 2006).

The following chapter of this thesis now focuses upon outcomes for these children. It highlights a number of issues, focusing particularly on the courtesy stigma they experience as a result of their parents social status. It then considers what may support them to negotiate difficulties and promote resilient functioning in the face of adversity.

Chapter 2: literature review

2.0 Indentifying the studies under review

The previous chapter highlights a number of difficulties experienced by parents with learning disabilities, which can contribute to fragile care-giving, and increase the potential vulnerability of their children. Despite this, there has been barely any research into outcomes for such children (*Good Practice Guidance on Working with a Parent with a Learning Disability*: Department of Health, 2007), or factors that may help promote resilient functioning (Booth and Booth, 1997).

One area which has received very little attention is that of courtesy stigma (Perkins *et al.,* 2002); discrimination which arises out of being associated with a discredited family member (Goffman, 1963). No research was found which considered what factors may protect children from this risk and promote healthy self-esteem - despite the fact that there are a number of well established core resilience variables; shown to promote adaptive functioning in children across a range of undesirable circumstances (Masten and Powell, 2007). The current research was therefore designed to address this gap in the literature.

The aim of this literature review was to consider the small body of research into outcomes for children and to examine the issue of courtesy stigma. Evidence on resilience factors was then reviewed.

Outcomes for the children of parents with learning disabilities
This search was conducted using NHS PsychINFO, MEDLINE, CINAHAL, EMBASE and HMIC online journal databases, between the years of 1970 and 2008. In addition a manual search was made through relevant published books. Search strategies included variations on the following terms: CHILDREN, PARENTS, LEARNING DISABILTIES, INTELLECTUAL DISABILITIES, OUTCOMES, RESULTS and TREATMENT. Section 2.1 of this chapter reviews five studies which

considered the genetic heritability of learning disability and nine which investigated other emotional, psychological and social outcomes for children.

Courtesy stigma

A search was carried out using the same journals as above and relevant books were reviewed. Search terms included variations on PARENTS, CHILDREN, RELATIVES, FAMILY, LEARNING DISABILTIES, INTELLECTUAL DISABILTIES, STIGMA, COURTESY STIGMA, EFFECTS and OUTCOMES. Section 2.2 of this chapter reviews three studies, which reported perceived stigma and acts of discrimination against the children of parents with learning disabilities. Nine further studies were examined, which considered courtesy stigma more broadly in relatives of individuals with a stigmatising social status.

Resilience

A search was again conducted using the online journal databases and relevant books. Search terms included variations on the following: CHILDREN, PARENTS, LEARNING DISABILTIES, INTELLECTUAL DISABILTIES, RISK, ADAPTIVE BEHAVIOUR and RESILIENCE. One study was found which examined resilience factors specifically for the children of parents with learning disabilities, but none on resilience to courtesy stigma. To explore potential protective factors further, the wider evidence base was reviewed. This identified a number of key personal, relational and external support system-based resilience variables (Masten and Powell, 2007). For the purposes of this research, two relational variables were selected for review; attachment and social support. Three personal variables were also considered; a child's age, gender and intelligence. Although these personal variables were not the main focus of the study, their inclusion allowed for a more detailed exploration of resilience. Section 2.3 reviews thirteen resilience studies.

As a result of the literature review, the current research placed particular emphasis on the role of child attachment to their mother as a protective factor against courtesy stigma. A summary of the literature on attachment interventions was therefore reviewed in section 2.4, in order to consider their applicability in clinical practice for the children of parents with learning disabilities.

Section 2.5 explains the reasons for this research. Section 2.6 then outlines the model for investigation: courtesy stigma was viewed as a risk factor to child development and self-esteem was considered as a measure of adaptive outcome. Attachment and social support were the main resilience variables for investigation.

2.1 Outcomes for children of parents with learning disabilities

There is a small body of research into outcomes for the children of parents with learning disabilities. In total, five studies were identified which considered the genetic heritability of learning disabilities; although several of these were conducted many years ago and little more recent evidence was identified (Dowdney and Skuse, 1993). A further nine papers were found which investigated social, emotional or behavioural outcomes for these children.

This literature suggests that rates of learning disability may be higher than average among this population (Accardo and Whitman, 1990; Brandon, 1957, Gillberg and Geijer-Karlsson, 1983; Reed and Anderson, 1973; Shaw and Wright, 1960) and that they may be at increased risk of developmental difficulties (Feldman *et al*, 1985; Feldman and Walton-Allen, 1997), psychological and social problems (Gillberg and Geijer-Karlsson, 1983; McGaw *et al.*, 2007), complexities within the parent-child relationship (Booth and Booth, 1997, Kohler and Didier, 1974; O'Neill, 1985; Perkins *et al.*, 2002) and maltreatment (Booth and Booth, 1997; Ronai, 1997). However, studies demonstrate a number of flaws in design, including small sample sizes, biases in participant recruitment and a lack of matched control groups, which limit the reliability of findings so that they may be generalised to the rest of the population. This research is reviewed below.

Learning disability

The prevalence rates of intellectual disability in the children of learning disabled parents vary between studies.

Dowdney and Skuse (1993) draw attention to studies by Brandon (1957) and Shaw and Wright (1960), which estimated child learning disability to be around 15%, whereas Accardo and Whitman (1990) and Gillberg and Geijer-Karlsson (1983) report a rate of 30% or more. These divergent outcomes are likely to result from

methodological differences between studies. Sample selection procedures resulted in different sample populations – where some included the children of high-functioning women (Brandon, 1957), others considered children whose mothers IQ fell only in the learning disability range (Geijer-Karlsson, 1983).

McGaw and Newman (2005) suggest the most reliable estimate of prevalence comes from an epidemiological study conducted by Reed and Anderson (1973). This investigation involved a large sample of eighty thousand participants. They found that (within the general parenting population) 1% of children had a learning disability where both parents were of average intelligence. They found that where one parent had a learning disability, this figure rose to 19%. Where both parents had a learning disability, 45% of children were of low to average intelligence. Conversely, 13% of children were found to have above average intelligence when one parent had a learning disability. In fact, 1% of children were found to have above average functioning, even where both parents had a learning disability.

Although there has been a limited amount of study on the subject, there is a broad consensus in the literature that exists that rates of learning disability will be higher amongst the children of parents with learning disabilities, although overall IQ will show a regression to the general population mean (Dowdney and Skuse, 1993).

It is important to note that while some learning disabilities will be genetically inherited, others may result from psycho-social disadvantage in general (Sinason, 1992). However, the role of psycho-social factors in the development of learning disability has yet to be elucidated (Dowdney and Skuse, 1993).

Developmental difficulties

The literature also suggests that children of parents with learning disabilities may be at further risk of developmental difficulties (McGaw and Newman, 2005), although there has been very limited empirical research into the issue.

A study carried out by Feldman *et al.* (1985) examined developmental delay in twelve children, aged 2 years old. They sought to examine the developmental domains most affected (cognitive, motor, language or social) by having a parent with a learning disability, as well as the influence of environmental variables on child development.

Their participants included twelve mothers, with an average IQ of 69, and their twelve children (7 of whom were girls and 5 boys). None of the children in this study had any apparent genetic, physical or neurological disorders associated with developmental disabilities. The Bayley Scales of Infant Development (Bayley, 1969) were used to assess infant development. The Caldwell Home Observation for the Measurement of the Environment (HOME) (Caldwell and Bradley, 1984) was used to evaluate the quality of maternal interactions in the home environment.

Child development was found to positively correlate with 'Maternal Involvement' on the HOME inventory. Interestingly, mothers who were more involved also scored more highly on the 'Avoidance of Restriction and Punishment' subscale of the HOME; suggesting that concerned mothers may be overly protective of their children. Children were found to be at risk of developmental delays, particularly in language, as early as 2 years old.

While the number of children with learning disabilities themselves (and therefore developmental delay) may be likely to be higher in this sample (due to genetic inheritance factors), Feldman *et al.* (1985) conclude that the quality of mother-child interactions are strongly related to child cognitive development.

Reliable, norm-referenced measures were used to evaluate child development and mother-child interactions in this study, but the sample was small and they did not use a control group matched for socio-economic status. Nor did they make it clear on what basis mothers were recruited to the study. Mothers known to services may be more likely to experience problems with their children; so it is difficult to gauge how representative of the wider population their sample might have been. Several factors therefore limit the generalisation of these findings, a problem which the authors themselves observe.

In a further study, Feldman and Walton-Allen (1997) investigated the effects of maternal learning disability and poverty on the intellectual, academic and behavioural status of school-age children. Their research included twenty-seven children between the ages of six and twelve years old who had a mother with a learning disability.

Maternal learning disability was defined as IQ of 70 or below, measured by the Wechsler Adult Intelligence Scale (Wechsler, 1997). A comparison group of twenty-five children participated whose mothers were identified as not having a learning disability. Both groups were matched for socio-economic status. Standardised measures were administered to the two groups of children and to mothers, in order to evaluate intellectual functioning, behaviour disorders, quality of the home environment and maternal isolation and support.

The children whose mothers had learning disabilities tended to have lower IQ's, poorer academic records and more behaviour problems. Not one child in the maternal learning disability group was problem free, and boys were more severely affected than girls, the quality of the home environment and of maternal social supports were also lower. Both the home environment and social support measures negatively correlated with child behavioural disorders measures. Feldman and Walton-Allen (1997) conclude that being raised by a mother with a learning disability can have a negative effect on child development, which cannot be attributed to poverty alone.

Although the sample size was small in Feldman and Walton-Allen's (1997) study, it was well designed, using standardised measures and a control group matched for socio-economic status. However, it may also be the case that factors other than those examined could influence child development for the children of parents with learning disabilities. Maternal mental health problems, for example, have been shown to relate to poor child outcomes (Hammen, Burge and Stansbury, 1990), and the prevalence of depression in particular has been shown to be high in adults with learning disabilities (Eaton and Menolascino, 1982).

The two studies cited above suggest that children of parents with learning disabilities may be vulnerable to developmental delay in infancy and poorer academic and behavioural functioning during early to late childhood. While increased risk of

developmental difficulties seems conceivable, there is a lack of empirical data to support this hypothesis, such that it may be generalised to the wider population.

Psychological and social problems

Two studies were found which indicated that the children of parents with learning disabilities may be at risk of mental health problems and poor social outcomes.

Gillberg and Geijer-Karlsson (1983) carried out a follow-up study of forty-one children, aged between one and twenty-one years old, born to fifteen learning disabled Swedish women. Mothers were known to the Board for Provisions and Services for the Mentally Retarded (BPSMR), an institution with which people with learning disabilities had to be registered, in order to receive full educational, vocational and economic provision from the State. It was estimated that two-thirds of all learning disabled people in Sweden were registered at the BPSMR, and that there was no major social class bias amongst those registered compared with those not known to BPSMR. All mothers in the study had tested IQ's, which fell in the 50-70 range. The mean age of the children was 9.8 years old.

Outcomes for the children were reviewed by examining registers of child psychiatric clinics and social services authorities. Case records were read and social workers, psychologists and child psychiatrists were interviewed. The data for these children was then compared with data for ten year old children in the general population (from the Swedish Central Bureau of Statistics, 1982).

In total, 85% of the children in their sample had severe current, or historical, psychosocial problems; only 15% had not been registered with services because of major psychosocial problems at follow-up. Gillberg and Geijer-Karlsson (1983) argued that this lack of registration should not be taken as proof that no psychiatric disorders were present, but rather indicated a lack of more detailed assessment.

This was a well designed study, in that the mothers were a representative sample of parents with learning disabilities, but the forty-one children were born to a small

sample of mothers (n=15). Gillberg and Geijer-Karlsson (1983) do not say how the mothers were selected for the study, nor do they detail if they had any other difficulties, such as mental health problems, which may have also impacted on child outcomes. They do not explain how they defined 'psychiatric/psycho-social problems' in the children, whether this was on the basis of a formal diagnosis in the case files, or simply being registered at a psychiatric clinic. As a child could be referred to a psychiatric clinic for a number of reasons, it may not be reliable to suggest this is evidence of severe psychological problems.

McGaw *et al.* (2007) carried out a study with fifty-eight children born to learning disabled parents. Using the Devereaux Scales of Mental Disorders (Naglieri, LeBuffe and Pfeiffer, 1994) to evaluate psychopathology, they found that 69% of children had one or more problems denoting some type of mental disorder. Overall, 40% reported multiple problems spanning several categories. The most frequently reported categories related to poor attention span (41%), conduct disorders (40%) and anxiety (24%). These findings indicate that the children of parents with learning disabilities may have higher levels of mental disorders than those reported in studies involving the general child population (Meltzer, Gatward, Goodman and Ford, 2000; Nagileri *et al.*, 1994). They also found that children were significantly more likely to have mental health problems when their parents reported poor mental health.

As discussed in the previous chapter, the study by McGaw *et al.* (2007) has several methodological weaknesses. The children who participated were known to a service due to their parents' difficulties with child-care skills. Poor parental care may have a relationship with child outcomes (such as conduct disorders, anxiety and attention problems). Accordingly the psychopathology these children displayed may not be representative of the wider population. Furthermore, no comparison group of children matched for key demographic data was used, the inclusion of which would have strengthened the reliability of findings.

The studies reviewed above suggest the children of parents with learning disabilities may be at greater risk of mental health problems than the general population. However, there is limited empirical research in this area so far and further investigations are needed.

Difficulties within the parent-child relationship

Outside parent skills training, the issue of the parent-child relationship has received very little attention in the literature to date, although four studies have begun this enquiry and report some interesting findings.

Kohler and Didier (1974) looked at the attachment between mother and child in five children whose parents were learning disabled. They identified poor 'ego-development' in the parents, which they describe as a lack of emotional and psychological maturity. This had a more significant impact on the quality of child attachment than either the learning disability itself or the concurrent deprived socio-economic status, so parental learning disability was not considered to be the key factor.

This paper took a theoretical, case study approach to examining outcomes among the children, so generalisation of these observations to the rest of the population is not possible. Sadly, a more detailed critique of Kohler and Didier's (1974) study is not possible here, as only the abstract (not the full article) was translated into English.

Perkins *et al.* (2002) carried out a study on the mother-child relationship with thirty-six average intelligence children of parents with learning disabilities, aged between nine and seventeen years old. They considered the child's perception of stigma in relation to their mother, the mother-child relationship, the number of roles a child possessed in their life (such as best-friend, student etc.) and the child's self-esteem. Mothers and children were recruited to the study via several agencies throughout New York, which provided services to parents with learning disabilities.

Mothers were assessed as learning disabled by the agencies involved in their care. The hypothesis was that a child's attachment to their mother would be less secure owing to the stigma they felt about their mother's disability, and that this in turn may have an effect on the child's self-esteem. However, they suggested that, where the mother's care-giving style was perceived as warm, the child's self-esteem would not be effected. They also proposed that if a child had a large number of relationships to call upon, none of the aforementioned relationships would hold.

Their findings partially supported their hypotheses. Perception of stigma was a significant predictor of attachment style – those who reported less perceived stigma reported more secure attachment to their mother. Although there was no significant relationship between secure attachment and higher self-esteem, they did report a significant relationship between avoidant and anxious/ambivalent attachment style and lower self-esteem. The hypothesis that the number of roles a child had in their life would moderate the relationship between attachment style and self-esteem was not supported. However, they did find the number of roles a child had was a significant predictor of self-esteem.

The Perkins *et al.* (2002) study demonstrated a number of methodological weaknesses. Their sample was small, not randomly selected and they did not use a control group. No information was given on how maternal learning disability was assessed, nor did they explain how they ensured children did not have a learning disability. They simply state that none of the children were in receipt of remedial school services, an approach which is unlikely to guarantee the absence of learning disability.

The measure of attachment used in the study was also concerning. The Hazen and Shaver (1987) Parental Caregiving Style Questionnaire used was originally designed to measure attachment in adult relationships. Its use with children to measure parent-child attachment raises issues of validity.

O'Neill (1985) also investigated children's relationships with parents, in a qualitative study. Twenty-three average intelligence children and their learning disabled parents were interviewed about their roles and relationships with one another. Parents were assessed as having a learning disability on the basis of professional opinion or educational history. Children were assessed as not having a learning disability on the basis of IQ scores and school reports.

Nearly half of the children had negative behavioural adaptations, such as rebelliousness, problems with social interaction and 'pseudo-retardation'. A quarter had taken over the parent role in the family, in essence becoming carers themselves.

Notably, none of the 'pseudo-retarded' children had any siblings, leading to the conclusion that such presentation may result from children imitating their parents. While an interesting investigation, there was no clear assessment of parental learning disability in this study - which may mean that children were included whose parents were low functioning for reasons other than learning disability (as is the case for parents with mental health or drug and alcohol problems). Consequently some of the issues identified may be faced by many children, whose cognitive functioning is superior to that of their parents.

Booth and Booth (1997) considered the parent-child relationship in a retrospective study with thirty adults, who had grown up in a family where one or both of their parents had a learning disability. Participants were aged between eighteen and thirty years old; half of the study had learning disabilities themselves. They were interviewed using the narrative method of 'life review', and were invited to reflect on and appraise their childhood experience.

The majority of participants expressed positive feelings about at least one of their parents. In total, twenty-five people said they were close to their mother, and in twenty-two of these cases the mother had learning disabilities. Only eleven expressed similar feelings towards their father, and twelve reported a distant relationship with their father. The rest had either not known, or had no contact with, their father during their childhood years.

Interestingly, every person in the study had maintained a relationship with their parent(s); even those who had spent time in care as a child had re-established contact with their parents later in life. Overall, two out of three also passed some negative comments about their mother and/or father. However, only eleven spoke critically about a parent with a learning disability.

Booth and Booth (1997, p.28) suggest that the information reported in their study 'challenges the prejudicial assumptions about the durability of relationships between children and parents with learning disabilities'. They conclude that 'people love their parents despite and not because of who they are'.

Although, it should be noted that participants in this study were located and contacted through their parents, which might suggest that the parent-child relationship was reasonability positive. It does not account for those who had lost touch with their parents or for the reasons why that may be. The data may therefore distort the picture in terms of parent-child relationships. Furthermore, half of the participants had learning disabilities themselves, which complicates the issue of accurate memory function and comprehension, particularly when recalling experiences from many years ago.

Overall, research in this area does not provide a consistent picture with regards to a child's relationship with their learning disabled parent. Some have suggested that a mothers' lack of emotional and psychological maturity may be of influence (Kohler and Didier, 1974) and that some children without learning disabilities themselves may be prone to assuming a quasi-parental role within the family (O'Neill, 1985). It also appears that a child's perception of stigma in relation to their parents' social status may effect the quality of their attachment to their mother (Perkins *et al*., 2002). Conversely, one study reported generally positive views of being cared for by a parent with a learning disability (Booth and Booth, 1997). Although, as with previous research reviewed, there are reoccurring themes in the methodological flaws of these studies and as such findings are to date inconclusive.

Maltreatment

Two studies were found that considered the experience of maltreatment from the child's perspective.

Ronai (1997) provided a powerful ethnographic account of what it was like to grow up with a learning disabled mother and a father who was a known sexual offender. She described a harrowing account of sexual abuse at the hands of both her mother and her father. She illustrated how services were unable to protect her, due to the web of secrets she was required to keep within the family.

Ronai's (1997) paper gives us insight into the complex emotional relationship a child may have to their abusing parents. Despite her experience, she described how she both loved and hated her mother. It serves as a reminder to professionals involved in child protection the vulnerability of such children. However, Ronai's (1997) personal experience cannot be seen as representative of the population as a whole, due to the individual nature of the study.

In the narrative study by Booth and Booth (1997), reported previously, sixteen participants experienced some form of sexual or physical abuse as a child. The majority of the maltreatment described was physical in nature; only one recounted sexual abuse. In over half of these cases the perpetrator of the abuse was said to be the victim's father, of whom only one had a learning disability. No mothers were cited for abuse.

In total, eleven people said they had suffered physical and/or sexual abuse by step-parents during their childhood, other than (or in addition to) that by their father. Almost twice the number of women than men had experienced some form of abuse; women with learning disabilities reported the highest frequency of maltreatment. Four women had been the victims of rape or incest as a child.

Booth and Booth (1997) observe that while the prevalence of abuse was high in their study, the perpetrator of that abuse was seldom a parent with a learning disability. In fact, it appeared that abuse most frequently occurred for girls with learning disabilities at the hands of an adult other than their parents.

These interesting studies provide insight into the issue of maltreatment, but, clearly, the research is very much in its infancy. However, investigating the experience of abuse and neglect from a child's perspective is a highly sensitive area, the investigation of which is difficult to justify ethically unless there is a benefit to the child. As such research in this area may remain limited.

Summary

So far we know little about outcomes for the children of parents with learning disabilities and there is recognition in the literature that this needs to change (*Good Practice Guidance on Working with a Parent with a Learning Disability*: Department of Health, 2007). The studies to date suggest they may be at increased risk of learning disability themselves (Accardo and Whitman, 1990; Brandon, 1957, Gillberg and Geijer-Karlsson, 1983; Reed and Anderson, 1973; Shaw and Wright, 1960), may have developmental difficulties (Feldman *et al*, 1985; Feldman and Walton-Allen, 1997), as well as psychological and social problems (Gillberg and Geijer-Karlsson, 1983; McGaw *et al*., 2007). The literature also suggests they may be vulnerable to maltreatment, particularly if female and learning disabled themselves, most probably at the hands of their father or of another adult known to their mother (Booth and Booth, 1997; Ronai, 1997). There is some evidence to suggest complexities within the parent-child relationship (Kohler and Didier, 1974; O'Neill, 1985; Perkins *et al*., 2002), although one study reported positive experiences of parenting by a learning disabled mother or father (Booth and Booth, 1997).

The findings of these studies have limited generalisability, due to methodological weaknesses in design. The sample sizes are typically small, and many participants were recruited via services to which their mothers or fathers were known due to parenting difficulties. Hence, the samples may not be representative of their population overall. Only one, Feldman and Walton-Allen (1997), used a comparison group matched for socio-economic status.

The common methodological issues with research in this area perhaps reflect problems with identifying this group of children. Locating children via services to which their parents are known may be a flawed approach, but the fact remains that it is difficult to trace these children through other sources.

Parents who are doing well are unlikely to come to the attention of services. In fact they may actively avoid doing so (Cleaver and Nicholson, 2008). There is no register of all learning disabled parents in the country and, indeed, it would be discriminatory

for there to be one. As such it is not easy to identify these children or assess outcomes.

One factor which children are likely to face regardless of whether or not their parents are known to services is the effect of their parents' social status. A learning disability is well understood to be a stigmatising label (Beart, Hardy and Buchanan, 2005); as a result of which their children may be vulnerable to stigma by association (Perkins *et al.*, 2002). The next section discusses the stigma of learning disability and examines the literature on the issue of associative stigma.

2.2 Courtesy stigma

People with learning disabilities belong to a stigmatised social group (Beart *et al*., 2005), as a consequence of which their children may be subject to stigma by association (Perkins *et al*., 2002). These children can be vulnerable therefore not only as a result of their parents' cognitive limitations, but as a result of society's discriminatory attitude to disability.

This section first defines the primary stigma of learning disability, in order to provide a context for the literature on stigma by association. Studies into courtesy stigma are then reviewed. One study was found which investigated courtesy stigma in the children of parents with learning disabilities (Perkins *et al.,* 2002). Two further enquiries with these children have also reported discrimination as a consequence of their upbringing (although not explicitly referred to as courtesy stigma), which were considered appropriate to include in this review (Booth and Booth, 1997; Ronai, 1997). The wider body of evidence on courtesy stigma was also considered.

Interestingly, there has been little empirical enquiry in this area; nine studies were identified which considered this issue for relatives of discredited individuals, including parents, siblings and children (Angermeyer, Schulze and Dietrich, 2003; Birenbaum, 1970; Burk and Sher, 1990; Corrigan, Watson and Miller, 2006; Green, Davis, Karshmer, March and Straight, 2005; Mehta and Farina, 1988; Norvilitis, Scime and Lee, 2002; Ostman and Kjellin, 2002; Wahl and Harman, 1989). They highlight several key themes which seem to be common to the experience of stigma by association.

The primary stigma of learning disability

Goffman (1963, p. 3) described primary stigma as an 'attribute that is deeply discrediting' and one that reduces the bearer 'from a whole and usual person to a tainted, discounted one'. A learning disability has long been seen as the cause of a stigmatised identity (Beart *et al*., 2005), which eclipses other salient aspects of the

individual - including gender, ethnic origin and religion (Walmsley and Downer, 1997).

Link and Phelan (2001) define five components which comprise primary stigma: labelling, stereotyping, separation, status loss and discrimination within the context of a power differential. Labelling refers to the way in which the individual is categorised as different in a socially significant way. This leads to stereotyping, where negative and undesirable attributes are assigned to those social differences. As a consequence, the discredited person experiences a sense of separation and 'otherness'. Status loss and discrimination occur when such stigma impinges upon an individual's ability to participate freely in their community, be that socially or economically. This arises in connection with a power differential; where those with the discredited attribute are less powerful than those without (Link and Phelan, 2001).

Primary stigma therefore consists of several elements, which relate to society's treatment of the individual (labelling and stereotyping) as well as its effects on the discredited person (separation, status loss and discrimination).

Beginning with the normalisation movement (Wolfensberger, 1972), attempts have been made to reduce the stigma of learning disability in our society. Indeed, it is against the law to discriminate against someone on the grounds of disability in the United Kingdom (*Disability Discrimination Act*: Office of Public Sector Information, 1995).

Despite this progress, there is still evidence to suggest the experience of stigma is intrinsic to this form of social identity (Beart *et al.,* 2005). For example, people with learning disabilities are frequently segregated from those without disabilities (Khan, 1985). They often receive statutory care from specialist learning disabilities teams rather than services for the mainstream population (Tarleton *et al*., 2006). They tend to have fewer opportunities in terms of employment (*Valuing People*: Department of Health, 2001) and are therefore disadvantaged economically (O'Connor, 1992). Where they do live independently, they often do so in disadvantaged neighbourhoods where their vulnerability makes them a target for others (Booth and Booth, 1997). They are less likely to marry (Koller *et al.,* 1994) or have satisfying social

relationships (Chappell, 1994). They also have fewer community leisure opportunities (Wertheimer, 1983) than people without learning disabilities.

When a person with a learning disability chooses to have children, such stigma may intensify and stereotypes can be exacerbated (Brown, 1994; Booth, 2000). The document *Good Practice Guidance on Working with Parents with a Learning Disability* (Department of Health, 2007) draws attention to the discrimination these parents face; bullying, harassment, violence and exploitation can be major problems (CHANGE, 2005).

It seems children who grow up in households headed by a learning disabled parent may have to contend with the damaging effects of their parent's social status.

Courtesy Stigma

The negative consequences arising from association with a stigmatised person have been termed 'courtesy stigma' (Goffman, 1963). It has also been described as 'associative stigma' (Gale, 2007). Its effects can be felt by any family member, as well as friends or neighbours of the discredited individual (Gale, 2007).

The experience of courtesy stigma has, however, received little empirical investigation to date. Given that Goffman (1963) first drew attention to the issue nearly fifty years ago, it is interesting to note that such a small body of literature exists. Most of it is concerned with courtesy stigma for non-disabled parents who have children with disabilities, or adult relatives of people with other stigmatising conditions, such as mental illness or drug and alcohol problems.

There has been barely any investigation of courtesy stigma from the child's perspective, regardless of the cause of their parents' stigmatised status (Link, Yang, Phelan and Collins (2004). Just three studies have referred to the discrimination which children of parents with learning disabilities may have to contend with (Booth and Booth, 1997; Perkins *et al.*, 2002; Ronai, 1997) and only Perkins *et al.* (2002) directly investigated the concept of courtesy stigma.

Investigations into courtesy stigma have largely taken an interview approach or devised questionnaires drawing on themes from the literature, using sample sizes ranging from n = 7 (Green *et al.,* 2005) to n = 487 (Wahl and Harman, 1989). Other investigators have identified the existence of courtesy stigma from the perspective of the non-stigmatised public, or college students. Sample sizes in these enquires have been substantial; ranging from n = 578 to n = 968 (Corrigan *et al.,* 2006; Burk and Sher, 1990; Mehta and Farina, 1988).

Many of these investigations have benefited therefore from large numbers of participants, but a lack of standardised assessments of courtesy stigma has meant it is difficult to generalise or compare findings across studies.

In analysing the body of literature on courtesy stigma, three key themes emerge: a distinction between perceived and actual courtesy stigma, its negative impact upon social relationships, as well as upon mental health and self-esteem.

Perceived and actual courtesy stigma

Perceived courtesy stigma refers to a sense in which an individual believes themselves to be discredited; actual courtesy stigma is the experience of discriminatory experiences at the hands of others. Research has shown they can operate quite separately; low actual courtesy stigma does not correlate with low perceived stigma.

Wahl and Harman (1989) carried out a study with four hundred and eighty-seven members of the National Alliance for the Mentally Ill (NAMI), across twenty different States in America. The participants were parents, spouses or siblings of a person with a mental illness. Questionnaires were mailed to NAMI affiliates, asking them about their experiences. Interestingly, a majority of respondents (56%) stated that courtesy stigma had a large impact on their lives, although a much smaller proportion (8-22%) identified specific ways in which they had been directly subject to discriminatory experiences. This study therefore highlighted an important distinction between perceived and actual courtesy stigma, although participants may have been particularly sensitised to courtesy stigma as a result of their NAMI membership; the philosophy of the organisation increasing their awareness of such discrimination.

The distinction between perceived and actual courtesy stigma was also identified by Norvilitis *et al.* (2002). They carried out a quantitative study with twenty-three parents whose children were diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). A control group of twenty-eight mothers who did not have children with ADHD were included in the study. A number of standardised measures were administered to investigate psychological well-being, in addition to which a twelve item questionnaire on courtesy stigma and ADHD, devised by the authors, was given to both groups of mothers.

They found the mothers of children with ADHD felt blamed and criticised for their child's condition, overall believing it to be more stigmatising for them than the control group perceived it to be. Perceived courtesy stigma was therefore considered to be a more significant risk to well being than actual discriminatory experiences.

More recently, Corrigan *et al.* (2006) carried out a study with the relatives of people with mental illness or drug dependence. Their sample included nine hundred and sixty-eight participants, randomly selected from the general public. In addition, a focus group was conducted with the family members of people with drug and alcohol problems, or mental illness, to examine the experience of courtesy stigma from their perspective.

Courtesy stigma was assessed by showing the public sample a vignette concerning a stigmatised individual and responses were assessed to ascertain the attributions people made about the stigmatising condition. Participants were also asked questions about stigma by association for family members, drawn from the literature and drawn from a focus group of seven family members, subject to courtesy stigma. These relatives reported feelings of blame, shame and contamination, which formed the basis of further interview questions.

Interestingly, the public rated stigma by association to be lower for family members, than was expected based on previous research. As such, relatives' perceived stigma was concluded to be a more significant factor than public attitude. Corrigan *et al.* (2006) describe how perceived stigma therefore contains a 'self-stigma', where the discredited social identity of the stigmatised family member is internalised by

relatives, a factor much more powerful than actual discriminatory experiences at the hands of others.

This interesting survey used a large sample, drawn from the general public. However, many of these participants held a bachelors degree or higher (24%). As education can increase awareness of social problems such as stigma and mental illness, some may have responded to questions in a socially desirable way. Consequently, their responses may not have reflected an accurate picture of courtesy stigma in the general public.

These three studies suggest courtesy stigma arises more from a subjective sense of being tarnished by the social status of the discredited family member, rather than actual discriminatory experiences.

Negative impact on social relationships

The literature suggests that courtesy stigma could negatively influence social relationships.

Social exclusion as a consequence of courtesy stigma was first identified by Birenbaum (1970), in a qualitative study with one hundred and three mothers whose children were learning disabled. Mothers' friendships were reported to be significantly diminished by having a disabled child. Few sought relationships with other mothers in similar circumstances. The author suggests that this may be a way of trying to manage courtesy stigma; friendships with others who are stigmatised do not support 'a normal appearing round of life, since they can be misinterpreted by others as an identification with one's fate' (Brienbaum, 1970, p, 201). If no within-group identification is sought, feelings of isolation can intensify.

One might expect this to have changed since 1970, with increasing awareness of the issue of stigma and disability. However, subsequent researchers identify similar themes:

Green *et al*. (2005) carried out qualitative interviews with seven mothers of children with disabilities and eight adults with disabilities, to explore the experience of

primary and courtesy stigma. They examined parents' narratives from the perspective of Link and Phelan's (2001) five components. Participants reported coping with the sometimes irritating experience of being labelled and stereotyped, and were able to resist or manage much of the status loss and discrimination encountered. The most destructive element reported was a pronounced sense of 'otherness', which was found to arise as a consequence of the separation component of stigma and led to a feeling of social isolation. This seemed to arise more as a consequence of perceived stigma than overt acts of being rejected or separated from others.

This study made no distinction between the experience of primary, as opposed to courtesy stigma and the implication is that Link and Phelan's (2001) five components are relevant to both experiences. It is interesting that the sense of 'otherness' reported seemed to be facilitated by self-stigma, rather than acts of direct discrimination.

Angermeyer *et al.* (2003) also found people's relationships were effected by courtesy stigma, in a study with the relatives of people with severe mental illness. In total, sixty-seven mothers, twenty-seven fathers, eleven wives, nine husbands, four brothers and four daughters participated in a number of small focus group discussions about the effects of stigma by association. Participants were drawn from the Federal Association of Relatives of People with Mental Illness (FARPMI) in Germany. The largest share of stigma and discrimination experienced by family members concerned social interactions with others; almost two-thirds (65.3%) of participants described difficulties in this area. As such courtesy stigma was seen to effect social support, although it is possible that relatives were more conscious of this issue as a result of FARPMI membership.

Ostman and Kjellin (2002) carried out a study with relatives of people with mental illness. Participants were drawn from families of a consecutive sample of patients admitted to a psychiatric service in Sweden. A semi-structured questionnaire was used to interview one hundred and sixty-two people, the items on which were drawn from the authors' clinical experience with this population. Findings demonstrated that relatives felt their own relationships and opportunities for social contact had been adversely effected by courtesy stigma. Yet it should be noted that participants in this study were relatives of people with severe mental illness, admitted to hospital. This

may have required their involvement in care and treatment, leading to a pronounced sense of social separation.

Social undesirability as a consequence of courtesy stigma has also been identified by Mehta and Farina (1988), who carried out a study with (non-stigmatised) college-aged students, showing them vignettes of young people whose fathers were either depressed, alcoholic or an ex-convict. The children with such fathers were viewed as less socially valuable than other groups of children. Similarly, Burk and Sher (1990) carried out a study with five hundred and seventy adolescents to examine their views of children whose parents were alcoholic or mentally ill. Children with a stigmatised parent were deemed to be socially discredited as a result of their parents' social status (Burk and Sher, 1990).

These investigations have drawn a link between courtesy stigma and social relationships. It seems courtesy stigma may contain a sense of separation, of 'otherness' and not belonging, similar to that described by Link and Phelan (2001). In this respect, courtesy stigma perhaps reflects a specific aspect of primary stigma.

Courtesy stigma and the children of parents with learning disabilities

One study has reported that the children of parents with learning disabilities are vulnerable to perceived stigma (Perkins *et al.*, 2002). Two others highlight the experience of actual discriminatory experiences at the hands of others (Booth and Booth, 1997; Ronai, 1997).

Perkins *et al.* (2002), (reviewed previously under section 2.1) evaluated children's perceived stigma in relation to their learning disabled mother with a group of thirty-six average intelligence children. Mothers were in receipt of services for their learning disability. They used a six-item questionnaire to examine courtesy stigma in children, based on themes within the literature which suggest that its manifestation is most evident in social interactions with others. The scale focuses on how comfortable children are to associate with their mother in public and how comfortable they are if

their friends interact with their mother. Cronbach's alpha for this scale was reported as 0.70, demonstrating moderate internal consistency (Perkins *et al.,* 2002).

They found that, where a child reported low levels of perceived stigma, they were significantly more likely to report a secure attachment to their mother. No significant relationship was found between perception of stigma and insecure forms of attachment.

The implication in the Perkins *et al*. (2002) study is that perception of stigma predicts secure attachment style. Yet the wider literature would suggest this relationship is more likely to work in reverse; insecure attachment is more likely to increase the risk of perceived discrimination, as it can broadly increase negative expectations of others (e.g. Howe, 2005). Furthermore, items on the Perception of Stigma Questionnaire were drawn from the literature, rather than from the views of children themselves, which may have influenced the results (properties of this questionnaire are discussed further in section 3.6 and 5.5 of the current research). Children who participated in this study were drawn from a service to which their parents were known due to their disability. This could have increased awareness of primary stigma, meaning participants may not have been representative of the children of parents with learning disabilities as a whole.

A qualitative investigation by Booth and Booth (1997) (discussed previously in section 2.1) found the experience of actual discrimination was commonplace for the children of parents with learning disabilities. In their retrospective study with thirty adults who had grown up with learning disabled parents, many reported being victimised and bullied during their school years. Seventeen of their participants reported being the butt of insults, taunting and verbal abuse. Twelve people said they could remember having to move house – some several times – in order to escape serious harassment and victimisation from others in their neighbourhood. Although the concept of courtesy stigma is not directly referred to, it is possible that some of this victimisation arose as a result of association with a learning disabled parent.

However, some of the participants in Booth and Booth's (1997) study were learning disabled themselves, so it is difficult to ascertain the degree to which acts of

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discrimination were due to primary stigma (as a result of being learning disabled) or courtesy stigma (as a result of association with their stigmatised parent).

In an ethnographic study, Ronai (1997) (discussed previously in section 2.1) describes how her mothers' social status could influence her friendships. Ronai herself was a bright child in a mainstream school. She describes how she would keep knowledge of her mother's learning disability away from friends, revealing it only when the friendship had developed to a point of trust. Even so, she found her mothers' disability could cause other children to terminate their friendship. Although Ronai's account is a personal narrative, it raises the issue of how such children may experience the effects of their mothers' social status, within the context of peer relationships.

Of these three studies, only Perkins *et al.* (2002) directly refer to the issue of courtesy stigma. Their research provides evidence of perceived stigma, although not of actual discriminatory experiences. It did not examine any other components which comprise associative stigma, but suggests it may influence a child's attachment relationship with their mother. Booth and Booth's (1997) qualitative approach and mixed sample of learning disabled and non-learning disabled children means findings can not be generalised, but highlights the risk of overt acts of discrimination for these children. Lastly, Ronai's (1997) ethnographic account can only truly be seen as reporting her own personal experience, but perhaps reflects a sense of separation and 'otherness' seen in the broader literature on courtesy stigma (Green *et al.,* 2005).

Taken collectively, these studies suggest that the children of parents with learning disabilities may be vulnerable to perceived stigma as a result of their parents' social status, and may also be at risk of overt acts of discrimination.

Courtesy stigma and its effects on mental health and self-esteem

Mental health

The primary stigma of learning disability has been shown to effect mental health (Dagnan and Waring, 2004; Szivos-Bach, 1993), it is not surprising therefore that three of the studies described above identified a relationship between the experience of courtesy stigma and mental health of family members.

Norvilitis *et al*. (2002) found mothers awareness of courtesy stigma positively correlated with increased rates of depression. Similarly, Green *et al.* (2005) found mothers sense of 'otherness' led to feelings of reduced self-worth and depression. Ostman and Kjellen (2002) found 40% of relatives believed courtesy stigma had resulted in them developing mental health problems themselves.

However, only Norvilitis *et al.* (2002) used a standardised measure to assess depression. Green *et al.* (2005) and Ostman and Kjellen (2002) both relied upon participants' subjective reports of their mental health, as such findings can not be generalised to the rest of the population.

No other studies were found which investigated the relationship between courtesy stigma and mental health.

Self-esteem

Research has shown that primary stigma can effect self-esteem for people with learning disabilities (Dagnan and Waring, 2004; Szivos, 1991). As yet, there has been little investigation into the effects of courtesy stigma upon self-esteem. Only Corrigan *et al*. (2006) and Wahl and Harman (1989) have considered this relationship.

Corrigan *et al.'s* (2006) findings were drawn from a focus group of family members experiencing courtesy stigma. Participants reported a sense of blame, shame and contamination as intrinsic to the experience of stigma by association - all feelings likely to lower self-worth (Corrigan *et al*., 2006). Similarly, in their survey of four hundred and seventy-eight relatives, Wahl and Harman (1989) found 21% of

participants reported their self-esteem had been significantly damaged by the experience of stigma by association.

However, issues within the methodologies mean it is difficult to generalise these findings to the wider population in question. The focus group aspect of Corrigan *et al.'s* (2006) study was a small qualitative investigation, and Wahl and Harman (1989) drew their sample from relatives belonging to NAMI, a result of which they may have been particularly sensitised to courtesy stigma.

No studies were found which considered the impact of courtesy stigma upon self-esteem in children at all, including the children of parents with learning disabilities. Although Perkins *et al*. (2002) considered these variables within their research, they did not examine the relationship between them. However, they do suggest courtesy stigma may manifest in negative behaviours: a child may 'act out, react to or interact with the mother in a manner that reflects the emotional turmoil created by this [courtesy stigma] perception. An ultimate consequence is that the child may have less positive feelings about him/herself' (Perkins *et al.,* 2002, p. 300).

How might courtesy stigma effect self-esteem?

It is necessary to understand what comprises self-esteem in order to see how it might be damaged by courtesy stigma.

A frequently cited definition of self-esteem from Rosenberg (1965) describes it as a 'favourable or unfavourable attitude towards the self'. However 'attitude' to oneself is not based upon our objective assessment of ourselves, but upon the judgments others make of us (Emler, 2001). Who we understand ourselves to be is determined by our interactions with others. Furthermore, we derive self-esteem not only on the basis of how others treat us, but from how we *imagine* others will treat us (Emler, 2001). It is not difficult to see, therefore, how courtesy stigma can have a negative impact upon self-esteem. This does not necessarily have to consist of direct discriminatory experiences. Perceived or self-stigma (Wahl and Harman, 1989;

Corrigan *et al.*, 2006), - i.e. how we imagine others think of us – presents a significant threat.

There is also a broader point to consider. While individuals make personal appraisals of themselves based upon how they believe others think of them, they also derive self-worth on the basis of the group to which they belong (Tajfel, 1978). The worth or status of the group effects assessment of self-worth. As such, our social identities are sources of self-esteem. For those who are associated with a discredited, stigmatised, group in society, self-esteem derived from group belonging can be poor.

However, Festinger (1954) argues that the status of the groups to which we belong can only be determined relatively – by comparison with other groups in society. Such comparisons are made on a lateral (others perceived as holding the same attributes as our group); downward (those considered to hold less favourable attributes) or upward basis (others viewed in a more favourable position) (Finlay and Lyons, 2000). In order to protect self-esteem, people will avoid upward comparisons (Festinger, 1954), yet this may not be easy for the children of parents with learning disabilities.

Where their parents may be able to make lateral or downward comparison to people with learning disabilities generally, children may find it more difficult to seek out a sense of group belonging, particularly if not learning disabled themselves. Indeed, avoiding identification with others in the same position has been seen as a coping strategy in order to protect a sense of a 'normal round of life' (Birenbaum, 1970).

Risks to self-esteem are of concern, as it plays an important role in competent functioning across a range of abilities and behaviours. For example, children with good self-esteem are more likely to possess effective social skills (Riggio, Throckmorton and De Paola, 1990; Burhmester, Furman, Wittenberg and Reis, 1988), enabling them to better develop friendship networks (Dolgin, Meyer and Schwartz, 1991).

Conversely, low self-esteem appears to predict a number of negative emotional, behavioural and social problems, in childhood and later life. It has been found to increase the likelihood of suicide attempts and suicidal thoughts (Reynolds, 1991),

risky sexual behaviour and teenage pregnancy (California Task Force to Promote Self-esteem and Personal and Social Responsibility, 1990), eating disorders (Veron-Guidry, Williamson and Netemeyer, 1997) and lower educational expectations (McFarlin and Blaskovich, 1981). It has also been shown to predict periods of extended unemployment (Feinstein, 2000).

It appears that if courtesy stigma presents a risk to self-esteem, there may be a number of potential negative consequences to the child.

Summary

Despite Goffman's (1963) early work on the social aspects of stigma, the influence of the normalisation movement (Wolfensberger, 1972) and the weight of legislation (*Disability Discrimination Act*: Office of Public Sector Information, 1995), it seems people with learning disabilities remain a stigmatised group in society (Beart *et al.*, 2005). Those who go on to have children may have to contend with an even greater degree of discrimination; their learning disability leads to a particular risk of prejudicial treatment when the support of statutory services is needed (Booth, 2000). As such, their children may be vulnerable to stigma by association (Perkins *et al.*, 2002).

There is only a small body of literature which has investigated courtesy stigma (Angermeyer *et al.*, 2003; Birenbaum, 1970; Corrigan *et al.*, 2006; Green *et al.*, 2005; Meta and Farina, 1988; Norvilitis *et al.*, 2002; Ostman and Kjellin, 2002; Wahl and Harman, 1989) and only three report on this issue for the children of parents with learning disabilities (Booth and Booth, 1997; Perkins *et al.*, 2002; Ronai, 1997).

Collectively, these studies investigated courtesy stigma using a range of different methods. Some used a focus group to draw out salient themes on the subject (Angermeyer *et al.*, 2003; Corrigan *et al.*, 2006), others interviewed people individually (Birenbaum, 1970; Davis *et al.*,2005), and others designed questionnaires with items drawn from the literature (Corrigan *et al.*, 2006; Norvilitis *et al.*, 2002; Wahl and Harman, 1989; Perkins *et al.*, 2002), or from clinical experience (Ostman

and Kjellin, 2002). Two studies used case vignettes to explore courtesy stigma from the perspective of non-stigmatised college students, to evaluate their perceptions of children whose parents had stigmatising conditions (Burk and Sher, 1990; Mehta and Farina, 1988). There were no standardised measures used and only one of the questionnaires was devised directly from a qualitative exploration of the subject (Corrigan *et al.,* 2006). The measurement of courtesy stigma, such that findings can be generalised, is still in its very early stages.

Although outcomes to date must therefore be viewed cautiously, the literature seems to suggest courtesy stigma is characterised by three different core issues:

- A distinction is made between perceived and actual courtesy stigma; it appears courtesy stigma does not simply arise as a consequence of actual discriminatory experiences at the hands of others. It is characterised by a self-stigma, where the discredited social identity of the stigmatised family member is internalised by relatives (Corrigan *et al*., 2006; Norvilitis *et al.,* 2002; Wahl and Harman, 1989).

- It may impact on social relationships (Angermeyer *et al*., 2003; Burk and Sher, 1990; Mehta and Farina, 1988; Ostman and Kjellin, 2002), even leading to feelings of social exclusion (Green *et al.*, 2005).

- There is tentative suggestion that courtesy stigma may also effect mental health (Green *et al*., 2005; Norvilitis *et al*., 2002; Ostman and Kjellen, 2002), and impact negatively upon self-esteem (Corrigan *et al*., 2006; Perkins *et al*., 2002; Wahl and Harman, 1989).

What we know about the relationship between courtesy stigma and self-esteem was gleaned from studies on the adult population (Corrigan *et al*., 2006; Wahl and Harman, 1989). Based on these findings, the current research hypothesised courtesy stigma may present a risk to child self-esteem.

If this hypothesis is correct, factors which promote resilience to courtesy stigma are a sensible focus for investigation.

Only one study to date has considered resilience at all in the children of parents with learning disabilities (Booth and Booth, 1997). The next section therefore reviews Booth and Booth's (1997) research and considers resilience for children faced with adversity, focusing upon several additional factors that may be pertinent to the children of parents with learning disabilities.

2.3 Exploring possible resilience factors

The previous section reviewed literature on courtesy stigma, drawing attention to its likely existence in the lives of children whose parents have learning disabilities. This section therefore examines what factors might protect children in such circumstances. The literature on resilience in the children of parents with learning disabilities was reviewed. One study was identified and, although it did not specifically address courtesy stigma, it did highlight the role of parental bonds and a supportive relationship with another adult (for both parent and child) in promoting good outcomes for these children (Booth and Booth, 1997).

No other studies were found which considered resilience in this population. The wider research was also reviewed. This identified a large body of evidence, which reports adaptive functioning to be promoted by a number of personal, relational and external support-system based variables; found to universally promote children's resilience, across a range of unfavourable risks to development (Masten, 2001; Masten and Coatsworth, 1998).

Drawing on Booth and Booth's (1997) research, as well as the wider literature, two main resilience variables were considered: a child's attachment relationship with their mother (henceforth referred to as attachment) and friendships with peers and adults (henceforth referred to as social support). To give the investigation a broader perspective, literature on three further protective variables was also reviewed: child age, gender and cognitive ability. These were chosen as they were considered to be state rather than trait variables; components of a child's life not dependant on other people or systems and therefore less vulnerable to the effects of other variables. However, in the current study, these resilience factors were given a secondary focus to attachment and social support.

Research into resilience has been extensive and the literature search identified a large number of studies. These were then analysed for their relevance to the circumstances of the children of parents with learning disabilities. Twelve studies were considered

appropriate for review (Bolger and Patterson, 2001a; Bolger, Patterson and Kupersmidt, 1988; Collishaw *et al.*, 2007; Cicchetti and Rogosch, 1997; Fergusson and Horwood, 2007; Flores, Cicchetti and Rogosch, 2005; Herrenkohl, Herrenkohl and Egolf, 1994; Kim and Cicchetti, 2004; Owens and Shaw, 2007; Perkins and Jones, 2004; Schwartz, Dodge, Pettit and Bates, 2000; Szalacha *et al.*, 2003).

Resilience research differs significantly from that carried out with the children of parents with learning disabilities. The populations involved are significantly larger, as well as easier to access. The findings are therefore more reliable than seen in much of the research reviewed so far. Studies tend to combine qualitative and quantitative methods within single investigations, consider multiple variables, use substantial sample sizes and often report outcomes assessed over many years (some from childhood to middle-age), in order to examine the nature of adaptive functioning over time. This review has drawn out salient points from each study identified. An overall critique of the methodologies is left until the end, so the investigations can be considered as a whole.

This section first defines resilience and then reviews Booth and Booth's (1997) study on the children of parents with learning disabilities. Subsequently it considers findings of the twelve resilience studies, with respect to attachment, social support, child age, gender and intellectual functioning.

Defining resilience

Traditionally study of child development has tended to categorise 'normal' versus 'abnormal' behaviour patterns. A resilience approach to child behaviour offers a strengths focused bio-psycho-social account. In clinical practice, resilience means 'looking for strengths and opportunities to build on, rather than problems, deficits or psychopathology to be remedied or treated' (Hill, Stafford, Seaman, Ross and Daniel 2007).

There is general consensus in the literature that two crucial conditions need to be present for resilience to be observed (e.g. Masten 2001; Luthar, Cicchetti and Becker, 2000; Gilligan, 2001):

- A significant risk must be present that has been associated with threats to child development and negative outcomes
- Positive adaptation in the face of that risk

Risks to child development are numerous, but include difficulties such as coping with mentally ill, alcoholic or drug abusing parents; as well as managing divorce, familial violence, maltreatment, poverty and discrimination (Masten, 2001).

Positive adaptation has been defined by a range of different outcomes. Some investigators have defined it as a child doing well at school, or displaying socially appropriate behaviours. Others have viewed it as the absence of psychopathology, healthy self-esteem or a low level of internalising problems (such as anxiety, depression, withdrawal and somatic complaints) and externalising behaviours (such as conduct disorders) (Luthar, 2007)

Beginning with the earliest research into resilience, a number of factors have repeatedly emerged that appear to protect children against threats to their development (Masten and Powell, 2007). These fall broadly into three domains:

- Individual attributes (such as intelligence, gender, self-regulation skills)
- Affectional ties (relationships within the family that provide support, from parents, siblings or other adults in the extended family)
- External support systems (whether in school, the community, church or workplace, that reward an individual's competencies and provide a support structure)

Resilience and the children of parents with learning disabilities

One study was identified which considered resilience factors for the children of parents with learning disabilities. This investigation by Booth and Booth (1997) has been discussed in previous sections of the literature review, as their interesting

qualitative enquiry revealed a number of different outcomes for children. In terms of resilience, they identified three aspects of the affectional ties domain (Masten and Powell, 2007), which support children to negotiate a range of difficulties they often have to face:

- Family ties, including the support of another adult other than their parents, usually from within the extended family
- Family supports, in order to ensure adequate care for the child. These might be through the extended family, or through services
- Enduring emotional bonds with parents

In reviewing these findings a number of difficulties are raised. They took a narrative life review approach, asking adults about their childhood experiences of being parented by a person with a learning disability. The key risk to child development was parental learning disability, but the effects of this are impossible to untangle from the consequences of socio-economic disadvantage and societal discrimination in general, something which the authors acknowledge. They were unable to define adaptive outcomes with any clarity, as some of their participants had learning disabilities, some did not. A person with a learning disability would not necessarily expect to have a job or a pass their driving test, where for the non-disabled group such attainments may be the hallmark of adaptive functioning.

Nonetheless, this was the first study of its kind and the resilience factors identified were in keeping with those highlighted in the wider body of resilience literature (Masten and Powell, 2007); affectional ties were found to promote good outcomes for these children. No further evidence on resilience and children of parents with learning disabilities could be identified. However, the broader literature on the topic was also reviewed, which provides some additional insight into resilience factors.

Identifying resilience factors

Building on Booth and Booth's (1997) research, literature on the role of affectional ties for children generally at risk of adversity was reviewed. No studies were identified which investigated affectional ties as resilience to courtesy stigma for any

group of children. However, the literature suggests that a number of individual attributes, affectional ties and external support system-based variables can act universally as protective factors, despite the context within which children face adversity (Masten, 2001).

This review therefore drew out key resilience factors, which have been well researched in the wider literature, in order to begin to consider their applicability for this population. Two aspects of the affectional ties domain were given a particular attention; child attachment to their mother and social support derived from peers and friends. While not the main focus of the study, three aspects of the individual attributes domain were also considered; a child's age, gender and cognitive ability. These were chosen as such attributes are likely to be stable at the time of a research investigation, and not liable to be influenced by any other variables – although it is noted that cognitive ability can be influenced by external factors such as good or poor parenting in early life (Rutter and Rutter, 1993).

Clearly this investigation does not therefore review all the potential resilience factors identified by Masten and Powell (1997). Rather, it provides a start point by focusing on specific variables, leading to the formation of hypotheses, which could then be tested to examine their relevance for the children of parents with learning disabilities. In total, five resilience variables are considered below.

Attachment as a resilience factor

Three studies were found which examined the role of attachment to mother in adaptive functioning. These studies have investigated attachment using psychometric measures to assess a child's bond with their parents, either in infancy (Owens and Shaw, 2007), during childhood (Kim and Cichetti, 2004), or retrospectively in adulthood (Collishaw *et al*., 2007).

The definition of attachment is first explained and these studies are then reviewed.

Defining attachment

Bowlby (1969; 1973; 1980) identified the quality of emotional ties between infant and caregiver in the first 3-4 years of life as an important predictor of emotional and psychological development for the child. These ties are described as 'attachment' (Bowlby, 1969; 1973; 1980) and have both a biological and psychological basis.

On the basis of interactions with parents, children build their own mental representations or internal working models of attachment relationships. As Ainsworth, Blehar, Waters and Wall (1978) describe, these mental maps comprise memories and expectations that provide children with the clues they need to predict how responsive and available their care-givers will be. Individual differences in attachment behaviour are hypothesised to be related to the behaviour of the primary attachment figure as opposed to child characteristics, such as temperament (Bowlby, 1969; 1973; 1980).

The patterns of attachment are broadly characterised as secure or insecure. Secure attachments provide what Bowlby (1969) termed a 'secure base' from which a child can explore its world. Attachment systems are continuous throughout life, with the individual taking their original 'blueprint' of the primary relationship into successive affectional ties.

While there is a strong tendency for the individual to maintain this original attachment style, Bowlby (1969; 1973; 1980) is clear that development is possible (in childhood as well as afterward) with the influence of new emotional relationships. These may change the individual's emotional and cognitive processes, enabling reinterpretation of past and present experiences, and revising the attachment behaviour system.

Howe (2005) describes how negative attachment experiences often leave children with an internal representation of others as unavailable, uninterested and unresponsive. The net result of this is a child has little emotional connection with others; reducing their social support. Howe (2005) explains that a further characteristic of insecure attachment is a child's inability to regulate their emotional arousal, leaving them overwhelmed at times of distress. This in turn can lead to a number of internalising or externalising behaviours.

Conversely, children with a secure attachment to their main caregiver are likely to develop confidence in their own abilities and trust the capacity of others to respond. Howe (2005) describes how children and adults with secure attachments are able to express their attachment needs without too much distortion or defence. There is an underlying expectation that attachment figures will be available when needed. The securely-attached child feels accepted and understood and is therefore able to develop an internal working model of themselves as valuable, promoting emotional and cognitive competence.

Caregivers who can create secure attachment tend to be empathetic and sensitive in their interactions with their child and able to regulate their child's distress when necessary (Howe, 2005). The child internalises parental coping mechanisms and, as he or she develops, is able to regulate their own emotional arousal.

Attachment as a resilience factor

Three studies were found which examine secure attachment as a protective factor for children faced with risks to development; there appears to be consensus that attachment can play a fundamental role in predicting better outcomes.

Owens and Shaw (2007) carried out a study into the role of attachment with three hundred and ten infant boys aged one and a half years old. Two-thirds of the families were living below the poverty line; all were of low socio-economic status. As such, poverty was viewed as the risk to child development. Adaptive functioning in this context was assessed on child behaviour and social skills.

Attachment was measured using Ainsworth *et al.'s* (1978) Strange Situation procedure. Secure attachment was found to predict better social skills and fewer behavioural problems in the participants. Indeed, children with secure attachment to their mothers were 2.5 times more likely to have sustained adaptive functioning five years later than those with insecure attachment. These findings suggest secure attachment is a significant resilience factor, which protects child development from the risks posed by low socio-economic status.

However, Owens and Shaw (2007) do not explain the processes by which attachment may facilitate adaptive functioning; how it enables a child to be resilient. Nor do they explain the processes by which poverty may bring about negative outcomes. The experience of poverty may be interwoven with a variety of different hardships, ranging from child malnutrition to maternal mental health problems. Indeed, where a parent has to contend with a mental illness in addition to being poor, then there could be an increased risk of attachment difficulties for their child. Yet these potentially significant influences on the mother-child relationship are not explored in this study.

Kim and Cicchetti (2004) also investigated attachment as a resilience factor in a comparison study of two hundred and six maltreated, and one hundred and thirty-nine non-maltreated, children aged between 7 and 12. Overall, 97% of the ill-treated group had suffered abuse and/or neglect by their biological mother. The investigation was carried out over a two year period; adaptive functioning was evaluated against children's level of self-esteem and their reported internalising and externalising problems.

Interestingly, they found that maltreatment and insecure maternal attachment variables were not significantly correlated; insecure attachment increased the probability of child maladjustment independently of maltreatment. Overall, insecure attachment to mother was found to correlate with lower self-esteem and higher levels of internalising problems, as well as externalising behaviours. Conversely, secure attachment was seen to correlate with higher levels of adaptive functioning in both the maltreated and non-maltreated groups of children.

Although secure attachment was related to better functioning, the finding that it could exist even in the context of the mother as perpetrator of the child maltreatment is not in keeping with previous research (e.g. Cicchetti and Toth, 1995). One explanation for this may be that the types of maltreatment were not identified in this study, yet significant differences exist between the effects of, for example, neglect as opposed to sexual abuse. The failure to isolate differing types of ill-treatment may have influenced research outcomes in this respect. Also, the processes by which secure attachment acts as a resilience factor were not addressed; exactly how it serves to protect children in the context of maltreatment.

Collishaw *et al.* (2007) conducted a study with five hundred and seventy-one adolescents who had suffered abuse and neglect and examined the role of attachment relationships in resilient functioning. This sample was followed-up again in adulthood, when five hundred and forty-one people participated. Adaptive outcomes were assessed using measures for psychopathology and personality functioning; resilience was evaluated against the quality of parental relationship and social functioning. Results were compared with those from a randomly selected control group.

In total, 44.5% of maltreated participants demonstrated no psychopathology at mid-life and were considered to meet the criteria for resilience. In this group, the quality of parental attachment, as well as peer relationships and adult friends were all strongly associated with resilience. Collishaw *et al*. (2007) conclude that good relationships with others outside the family were not simply determined by the good fortune of meeting a supportive friend, but were likely to be as a result of early parent-child experiences. As such, this study not only highlights the role of parental attachment in adaptive functioning, but indicates the likely influence of attachment upon an individual's subsequent relationships. Again though, the ways in which secure attachment may facilitate better functioning were not explored.

It is interesting to note a lack of exploration as to exactly how secure attachment facilitates better outcomes, in each of the three studies reviewed above. Attachment theory would suggest that secure attachment creates an effective internal working model for the child, which allows them to better regulate their emotional arousal and promotes a sense of self-efficacy (Howe, 2005). Yet, exploration of these processes, in terms of resilience, is missing from the research.

Nonetheless, there seems to be consensus in the literature that secure attachment to a primary care-giver can be significant in promoting resilience. As Yates, Egeland and Sroufe (2007, p. 255) describe, 'in our view of resilience as a process, the successful negotiation of early developmental issues, such as parent-child attachment in infancy, provides the foundation for positive adaptation among children exposed to adversity'. Indeed, this suggestion is reflected in Booth and Booth's (1997) finding that family ties are of greatest significance in terms of positive outcomes for children.

A hypothesis was therefore formed for the current research, that secure attachment to mother may act as a resilience factor for children of parents with learning disabilities; with respect to courtesy stigma as a risk to adaptive functioning.

Social support as a resilience factor

Children's peer relationships are one aspect of their social support system. The role of such relationships in resilience has been explored by a number of investigators, using a range of psychometric measures. Five studies were found which evaluated different aspects of friendship: Bolger and Patterson (2001a) considered friendship quality and reciprocity, Flores *et al.* (2005) considered the number of reported friendships and Bolger *et al.* (1988) investigated peer acceptance in addition to friendship quality. Similarly, Schwartz *et al.* (2000) assessed peer and group acceptance and Perkins and Jones (2004) examined the nature of children's peer group characteristics. These different aspects of peer relationships have been shown to influence resilience.

The definition of social support is first explained and these studies are then reviewed.

Defining social support

Social support is a multi-dimensional concept, which includes sources of support (friends, family and strangers) as well as type of support (emotional concern, instrumental aid, information about the environment or appraisal which helps a person to evaluate themselves) (House, 1981).

Two main theoretical models explain the value of social support. First, that it acts as a 'buffer', moderating life stresses for the individual. Second, that it provides a 'main effect'; directly benefitting well-being by fulfilling basic social needs (Williams, Barclay and Schmied, 2004).

There is no definitive definition of social support (Williams *et al.*, 2004), but it is commonly described as 'the existence or availability of people on whom we can rely,

people who let us know that they care about, value and love us' (Sarason *et al*., 1983, p. 127).

The literature suggests that the ability to seek support from others may be influenced by attachment. As Sarason *et al*. (1983) explain, there is an association between an individual's original attachment style to their main caregiver and their ability to seek and utilise social support in subsequent relationships. They suggest that, in effect, attachment to a primary care-giver in the early stages of life is the first level of social support an individual experiences. Where that support is effective, the individual learns to seek it and in turn offer it to others.

Mikulincer, Shaver and Pereg (2003) identify different attachment styles, corresponding to different levels of social support. They found that those with a secure attachment style were likely to have positive expectations about others' availability in times of distress, increasing their use of support when necessary. On the other hand, those with insecure attachment tended to exaggerate threat and held negative beliefs about interactions with other people, reducing the likelihood that they will seek help when faced with adversity. As Toldsdorf (as cited in Pretorius, 1993) explains, insecure attachment can cause a 'negative network orientation'; where the individual believes it is inadvisable, impossible, useless or potentially dangerous to draw on social support.

The nature of a child's primary attachment is therefore likely to influence the number and quality of peer supports in their life (Collishaw *et al*., 2007).

Social support as a resilience factor
Five studies were identified which found that, where peer support can be utilised, it can act as a protective factor for children exposed to adversity.

Bolger and Patterson (2001a) investigated the role of friendships quality and reciprocity in resilience, in a study with one thousand nine hundred and twenty children. Children were assessed on three occasions over a four year period, at which their modal ages were 8, 9 and 10 years, respectively. The study identified associations between specific aspects of child abuse and patterns of children's

adjustment, including their levels of self-esteem, the degree of internalising and externalising behaviours and the quality of their peer relationships.

High levels of good quality, reciprocal friendships were seen to act as a moderating variable between the experience of ill-treatment and low self-esteem. This was seen to manifest itself via a decreased sense of loneliness and an increased sense of social acceptance. Friendship was found to be especially important for children who had been abused over a long period of time. However, they found that children who had been chronically abused and/or neglected were likely to have problems in their peer relationships and less likely to have a best friend.

In a smaller longitudinal study, Bolger *et al.* (1988) examined the role of peer acceptance and friendship quality in resilience, with one hundred and seven children who had experienced maltreatment. Participants were identified via the child abuse and neglect information system in Virginia, United States. A control group of non-maltreated children was selected via school records in the same State. A child's positive adaptation, despite maltreatment, was evaluated against their reported level of self-esteem.

High quality friendships were found to moderate the relationship between the effects of the abuse and self-esteem. This remained the case over time; those with good quality friendships were three times more likely to meet the criteria for resilience one year later. However, children who had experienced chronic abuse were least likely to have support of any kind from peers. Interestingly, this pathway from maltreatment to peer rejection was substantially mediated by aggressive behaviour.

These findings were therefore in keeping with Bolger and Patterson (2001a). It seems that children who have been chronically maltreated are significantly less likely to have supportive peer relationships. This perhaps reflects damage which occurred in the original attachment relationship, leaving children less likely to seek support from others (Mikulincer *et al.*, 2003) and more likely to externalise distress by acting aggressively.

Schwartz *et al.* (2000) found that children who experienced a punitive, harsh, stressful and potentially violent home environment were at greater risk of being bullied by their peers. In examining factors which promote resilience in such circumstances, they considered the role of peer acceptance as a moderating variable. All participants were between 4 and 5 years of age and their families were considered to be of low socio-economic status. The research was split into two separate studies. Study one was conducted with three hundred and eighty-nine children; study two with two hundred and forty-three children.

The nature of the home environment was assessed via a one hundred and fifty minute interview with the child's mother. Key themes were drawn out of the interviews: harshness of discipline, marital conflict, stress and abuse. Ratings were then given on each of these aspects of the child's home environment.

Peer acceptance was conceptualised as a resilience factor and measured by asking children how many children they liked and disliked in their class. Peer victimisation was established by expanding the peer group support interview to include questions such as 'who gets picked on' and 'who gets hit'. Low levels of peer victimisation despite a harsh home environment was identified as the adaptive outcome.

They found that children who reported a significant reciprocal friendship were less vulnerable to being bullied by their peers. However, this study assessed peer group relationships on the basis of classroom friendships only at one fixed point. As the dynamics within children's peer groups at school (particularly with young children) are often subject to change, the effects of peer relationships in promoting resilience over time are important to understand, yet are not explored.

While the research suggests friendships can act as a resilience factor, evidence has also indicated that the particular attributes a friend possesses are important.

Perkins and Jones (2004) conducted a survey with sixteen thousand, three hundred and thirteen adolescents from a large mid-western State in America. They examined the relationship between physical abuse and risk behaviours (such as alcohol and drug abuse, tobacco use, sexual activity, suicidal behaviours, anti-social behaviour,

delinquency and purging). Although peer support was found to be a strong predictor of resilient functioning, they also identified that close friends who engaged in risky behaviours were in fact detrimental to maltreated adolescents' adjustment.

Supportive friendships with other adults outside of the immediate family are often cited as a major resilience factor for vulnerable children (Masten and Powell, 2007). Indeed, Booth and Booth (1997) suggest such relationships can be particularly important for the children of parents with learning disabilities. However, the literature reports contradictory findings.

Flores *et al*. (2005) carried out a study of resilience in a group of seventy-six Latino children living in the United States of America, who had experienced abuse and neglect. A comparison group of fifty-seven non-maltreated Latino children, matched for socio-economic status, were included in the study. Children had a mean age of 8.68 years old. They found that a child's ability to form a relationship with a camp counsellor differentiated resilient from non-resilient maltreated children. Yet it was notable that the child's personal characteristics accounted for most of the variance in adaptive functioning, rather than adult support outside of family members.

Perkins and Jones (2004) (discussed previously) found that having a close friendship with an adult outside the family was in fact associated with risky behaviours in children (such as alcohol abuse, tobacco use, drug use, sexual activity and suicide). However, children who demonstrated a close relationship with another adult outside of the family also tended to report reduced support within the family home. It may be the increased risk behaviours were therefore attributable to higher externalising behaviours as a consequence of disturbed family dynamics, rather than to a close relationship with another adult.

Overall, the literature suggests that where a child possesses the confidence to seek support, constructive peer relationships may act as a resilience factor. However, this does not seem to be the case for children who have been chronically abused and/or neglected. Such children seem to be particularly vulnerable to a *lack* of peer support. While there is some evidence to suggest that the availability of another reliable adult

can promote adaptive functioning for the children of parents with learning disabilities (Booth and Booth, 1997), the wider literature on this point appears inconclusive.

On the basis of the above research, it was hypothesised that supportive peer relationships may act as a resilience factor for the children of parents with learning disabilities, faced with the risk of courtesy stigma.

Age of the child as a resilience factor

Only one study was identified which examined the role of a child's age in resilience. However, its findings may have particular significance with respect to courtesy stigma, as this study was carried out with children at risk of racial discrimination.

Szalacha *et al.* (2003) looked at the relationship between child age and perceived racism in their study with two hundred and ninety six Puerto Rican youths living in the United States. They found that 6-8 year old children had a low likelihood of perceiving racism (12% of their sample), whereas almost half of their sample (49%) of 13-14 year olds reported racism. They also found adolescents' high perceived discrimination reported lower global self-worth. A negative association was seen between adolescents even worrying about the potential for discrimination to occur, and low self-worth.

In this study young children were therefore less likely to perceive racism than adolescents. This implies a certain level of cognitive development is needed to perceive discrimination, as it requires 'the ability to classify the self and others on multiple dimensions, the capacity to take differing perspectives necessary for understanding the principle of unjust treatment, and formal operational reasoning required to judge whether the same behaviour elicits different responses from people' (Szalacha *et al.*, 2003, p. 422). On this basis, a child would need to be capable of 'concrete operational reasoning' (Piaget, 1999) in order for them to understand the issue of discrimination. Within Piaget's developmental theory, this stage of reasoning normally occurs between the ages of 7 and 11 years old. It would seem that young children are therefore less likely to perceive racism.

However, an alternative explanation for Szalacha *et al.'s* (2003) finding is that exposure to stigmatisation may possibly accumulate as a child grows up. Fewer younger children may report discrimination, as they have not lived long enough to be subject to such experience.

While there will clearly be significant differences in the discrimination faced by ethnic minorities and the children of parents with learning disabilities, there may also be similarities if cognitive development is a determinant of perceived stigma. On the basis of Szalacha *et al.'s* (2003) research, it was hypothesised that adolescent children of parents with learning disabilities may be at greater risk of perceiving courtesy stigma than younger children.

The influence of gender in resilience

Masten and Powell (2007) suggest differences are apparent in the coping styles of males and females. Where females are more prone to internalise distress, leading to responses such as depression and anxiety, males are more likely to externalise responses, increasing acting out behaviours such as conduct disorders. One large study was identified for review which examined this issue in depth.

Fergusson and Horwood (2007) carried out a longitudinal investigation with one thousand two hundred and sixty-five children. The cohort was studied at birth, at 4 months, at 1 year, at annual intervals to 16 years and at ages 18 and 21 years. Data was collected from a combination of sources, including parental interviews, psychometric tests, teacher reports, medical records and police records.

Several standardised measures were used to evaluate the existence of psychopathology with respect to symptoms of depression and anxiety, conduct disorders, suicidal behaviours and criminal offending. Measures of childhood adversity included family socio-economic status, parental education, parental change and conflict, child abuse exposure and parental adjustment. Resilience was assessed on gender, the quality of parental attachment and parental bonding, peer relationships and academic attainment.

Over the course of the study, females demonstrated a lesser tendency to externalise responses to adversity; they were less likely to be drug or alcohol dependent, have conduct disorders or commit criminal offences than males. Males were less likely to internalise responses, such as depression, anxiety and suicidal behaviours. Consequently outcomes indicated the presence of gender-specific strengths and weaknesses in response to adversity.

Such gender differences could be explained by cultural influences. In Western culture, males are more likely to be encouraged to behave in ways that demonstrate self-containment, toughness and separation, resulting in a reluctance to demonstrate emotional vulnerability. Consequently a narrow range of affect is displayed, one which often manifests as anger, increasing externalising responses (Jordan, 2006).

Conversely, females are generally more encouraged towards a relational response to adversity (i.e. talking about personal distress with friends), and are more likely to internalise distress and blame themselves for failures than males. As a consequence, females may be more vulnerable to internalising responses (Jordan, 2006).

Indeed, some support for this suggestion is found in the wider literature.   Kling, Hyde, Showers and Buswell (1999) carried out an extensive meta-analysis of two hundred and sixteen studies into self-esteem and gender. They concluded that, although the effect size was small, females consistently showed lower levels of self-esteem (internalising response) than males, particularly during adolescence.

Drawing on the above research, it was hypothesised that male and female children of parents with learning disabilities may show differences in their responses to courtesy stigma; females may be more likely to internalise their experience, reducing self-esteem.

Intelligence as a resilience factor

The literature broadly suggests that higher levels of intelligence can protect children against risks to development (Masten and Powell, 2007), although there are some conflicting findings on this issue.

Flores *et al*. (2005) used receptive vocabulary as an indicator of cognitive ability in a study of resilience in a group of seventy-six ethnic minority children who had experienced abuse and neglect. A comparison group of fifty-seven non-maltreated children, matched for ethnic origin and socio-economic status, were included in the study. Resilient functioning was identified by examining children's ego-resiliency (the capacity to regulate one's level of ego control in response to situational triggers), ego-control (the inhibition or expression of an impulse) and receptive vocabulary. In addition, composite scores were created from nine measures of social competence and behavioural symptomology.

Flores *et al.* (2005) found that maltreated children evinced lower levels of ego-resiliency and receptive vocabulary than the control group. For both groups, higher ego-resiliency and moderate 'ego-overcontrol' were associated with more resilient functioning. Being female was also associated with higher resilient functioning. Nonetheless, they did not find receptive vocabulary (and therefore cognitive ability) to predict resilient functioning in the maltreated group.

It should be noted that the finding that receptive vocabulary was not a predictor of resilience in the above study may have been due to the low validity of the vocabulary measure for this ethnic group, due to language and acculturation issues.

In a longitudinal enquiry into resilience factors, Herrenkohl *et al.* (1994) studied the role of intelligence in resilience, with a group of children who had been abused or neglected. Children were assessed during elementary school and again in late adolescence. At the elementary school-age phase of the study, four hundred and fifty seven children participated.

Resilience was assessed in terms of cognitive/academic functioning as well as on social, emotional and physical functioning. At the adolescent phase, three hundred and forty five children participated; resilience was evaluated against school achievement, work history, relationships with peers and social functioning. Results were examined by splitting the cohort into high, low and middle functioning groups and outcomes were compared within groups, as well as against a control group.

Average or above average intellectual ability was found to be a predictor of school success. Interestingly though, it was in fact a less powerful predictor than either socio-economic status or parenting behaviours. Indeed, while higher cognitive ability in elementary school was associated with a greater likelihood of earning a college degree, this outcome was not guaranteed. Only 61% of the children who had exhibited better than average functioning in elementary school had attended or graduated from high school at the time of the adolescent interview. As such intelligence was not seen to predict resilience over time. However, it should be noted that Herrenkohl *et al.* (1994) used high school attendance as a criterion of success and it is possible that some may have dropped out of school for unknown reasons and yet still have maintained adaptive functioning.

Cicchetti and Rogosch (1997) investigated intelligence as a resilience factor with two hundred and thirteen children who attended a summer camp over a three year period. One hundred and thirty-three children who had experienced abuse and neglect were included in the study. Results were considered against a comparison group of eighty non-maltreated children, matched for socio-economic status and other demographic characteristics.

Participants were given a battery of measures to assess resilience on intellectual and interpersonal functioning, as well as psychopathology. Specifically, receptive vocabulary was used as the measure of intellectual functioning. The study was conducted on three separate occasions over three years. At the first stage of the study, children were aged between 6 and 11 years old. Abused children were consistently found to exhibit lower intellectual functioning than the control group. However, abused children who were deemed resilient demonstrated a higher intellectual functioning. Despite this, intelligence was not a predictor of sustained adaptive

functioning over a three year period amongst those who had suffered abuse. In fact, ego-control and self-esteem emerged as the most significant predictors of resilience.

Overall, evidence suggests that intelligence may have a significant role to play in resilience. Still, the processes by which it serves as a supportive function are not yet fully understood. It seems likely that the relationship between intelligence and adaptive functioning is mediated by a number of other variables, such as ego-control. Indeed, Luthar (1999) argues that even intelligent children, who become overwhelmingly anxious due to life events, may lose the advantage of high cognitive functioning.

The role intelligence plays in resilience is complex. However, on the basis of the above studies, it was hypothesised that higher cognitive ability may increase the likelihood of adaptive functioning for the children of parents with learning disabilities faced with courtesy stigma.

Methodological issues with resilience research

The strength of the resilience studies is they use large sample sizes, assessing a range of variables using quantitative and qualitative methods. However, the research reviewed presents a number of issues, which either impact on outcomes or make comparisons across studies problematic.

The literature was selected on the basis of specific resilience variables: attachment, social support, age of the child, gender and intelligence. These variables have been found to promote resilient functioning across a range of risk domains (Masten and Powell, 2007). Yet viewing the literature from the standpoint of resilience variables means the operational definitions of risk vary across studies, as do the definitions of positive adaptation:

- Some defined risk as the experience of racial discrimination (Szalacha *et al*., 2003) or of neglect and abuse (Bolger and Patterson, 2001a; Cicchetti and Rogosh, 1997; Collishaw *et al*. 2007; Flores *et al*., 2005; Herronkohl *et al*., 1994 Kim and Cicchetti, 2004; Perkins and Jones, 2004). Others

conceptualised risks to development as the experience of poverty (Owens and Shaw, 2007) or peer victimisation (Schwartz *et al*., 2000). On the other hand Fergusson and Horwood (2007) considered a large number of risk variables, including socio-economic status, parental education, parental change and conflict, child abuse and parental adjustment.

- Positive adaptation was conceptualised in several ways. A number of investigators have defined it as a child doing well at school, or displaying socially appropriate behaviours (Herrenkohl *et al.,* 1994; Owens and Shaw, 2007). However, others have focused on a combination of the absence of psychopathology, healthy self-esteem or a low level of externalising and internalising responses for the criterion of positive adaptation to be met (Cicchetti and Rogosch, 1997; Collisahw *et al.,* 2007; Fergusson and Horwood, 2007; Bolger and Patterson, 2001a; Bolger *et al*., 1988; Kim and Cicchetti, 2004).

Clearly, many of these risks differ from those inherent in courtesy stigma. As do a number of the different positive adaptations listed above differ from self-esteem. However, the implication in the literature is that identified resilience factors can protect children across a number of risks to development, broadly promoting adaptive functioning (Masten and Powell, 2007). Consequently, it is possible that they may promote resilience in children at risk of courtesy stigma.

There is a particular issue with the operational definition of risk across all resilience research; it is difficult to study the effects of one variable without the compounded effects of other multiple risk factors impacting on findings. For example, Owens and Shaw (2007) viewed poverty as the risk to child development, but did not explore the way in which it may effect functioning. Poverty may encompass malnutrition, poor housing, maternal mental health problems, bad quality schools etc. Yet teasing out these different components becomes too complex for one investigation to address. Nonetheless, some investigators have tried to address multiple risk factors (Fergusson and Horwood, 2007), although studies of this depth appear to be scarce.

Another methodological issue presents itself in the way researchers have analysed the data. Some have made comparisons within the research sample (Herrenkohl *et al*., 1994; Owens and Shaw, 2007; Schwartz *et al.,* 2000; Szalacha *et al*., 2003), others have made between-groups comparisons (Flores *et al*., 2005; Kim and Cicchetti, 2004) or have based it on norm-referenced scores (Collishaw *et al*., 2007). Different methods of examining the data make it difficult to compare findings across studies.

Longitudinal studies such as Fergusson and Horwood (2007) and Herrenkhol *et al.* (1994) were conducted over several intervals over the course of many years, where others were carried out at just one point in time (Schwartz *et al*., 2000). Obviously, the findings of the longitudinal studies are able to provide a picture of a child's resilience over time, which those that were carried out at one fixed point are not. Lastly, some do not report how they recruited their sample so it is difficult to know if they are representative of their population (Kim and Cichetti, 2004; Szalacha *et al.,* 2003).

Summary

The literature on resilience in the children of parents with learning disabilities was reviewed and one study was identified (Booth and Booth, 1997). Building on Booth and Booth's (1997) findings and drawing from the wider literature, five potential resilience factors were isolated for further review: parental attachment, social support, age of the child, gender and intelligence. On the basis of this literature, a number of hypotheses were formed for investigation in the current study.

There is consensus in the literature that secure attachment to a primary care-giver can be significant in promoting resilience (Masten, 2001), and may influence the extent to which children are able to seek peer support (Collishaw *et al.,* 2007). Consequently, the current research focused upon a child's attachment to their mother as a major component of resilience. As this study formed the basis of a practitioner doctorate, it was necessary to consider whether secure attachment could be promoted via clinical intervention with the children of parents who have learning disabilities. The next section considers an overview of the findings on attachment interventions.

2.4 Implications for practice: attachment interventions

Overview of research findings: effectiveness of attachment interventions

Genes and biology influence a child's temperament and are likely to have an effect on the parent-child bond (Neville and Johnson, 1997). Another significant influence on the relationship is the degree to which parents are emotionally and physically available to their children (Prior and Glaser, 2006). Evidence suggests that a parents' ability to offer consistent care-giving can be influenced by their own attachment history (Prior and Glaser, 2006). Indeed, research has identified a trans-generational conveyance with attachment; where a mother has an insecure attachment style (on adult attachment measures), there is a 70% likelihood of her child demonstrating the same (on child attachment measures) (Van IJzendoorn, 1995).

As such, individual differences in a child's attachment behaviour can frequently be predicted by the behaviour of the parent (Prior and Glaser, 2006). Attachment interventions therefore focus on developing a mother's responsiveness to her child, in order to facilitate secure child attachment (Prior and Glaser, 2006).

Prior and Glaser (2006) observe that the focus on mothers has excluded fathers. Perhaps this is because, historically, mothers have been the main caregivers to young infants. Although gender roles are no longer rigid as they were, it is still more common for the mother, rather than the father, to provide the majority of infant care. Attachment research that requires significant numbers of participants therefore necessarily draws on mothers.

Attachment-based interventions have tended to focus on two key aspects of the maternal relationship with their child:

- Developing insight into how their own experience of being parented has shaped their responses in relationships - including interactions with their children.

- Enhancing sensitivity and responsiveness, which involves facilitating appropriate parental behaviour in response to their children's needs.

Bakermans-Kranenburg, van IJzendoorn and Juffer (2003) carried out the most extensive meta-analysis to date on attachment interventions. They reviewed eighty-one studies which focused on enhancing maternal sensitivity and twenty-nine which assessed the effectiveness of interventions designed to promote child attachment security. The families included in this meta-analysis were largely drawn from clinical or at-risk populations. However, a small number were middle-class families with healthy children.

Prior and Glaser (2006) summarise Bakermans-Kranenburg *et al.,'s* (2003) findings of this meta-analysis:

Interventions designed to promote maternal sensitivity:

- The effect of intervention on maternal sensitivity in studies was moderate but significant. The effect size for all eighty-one studies was 0.44, a moderate effect.

- Interventions designed to promote care-giver sensitivity were effective, particularly when video feedback was used to enable mothers to reflect on their parenting behavior.

- Interventions of 5 sessions or less were as effective as those with 5 to 16 sessions and more effective than interventions with more than 16 sessions.

- Interventions carried out with mothers whose children were older than six months were more effective than prenatal interventions or those carried out in the first six months of the child's life.

- The effect of interventions conducted at home was not significantly different to those carried out elsewhere.

- The success of the outcome was not influenced by the mother's socio-economic status.

- Interventions from non-professionals were more effective than those from professionals.

Interventions to promote secure child attachment:

- Attachment focused intervention studies showed a small but significant effect ($p < 0.05$).

- Interventions that were most effective in enhancing child attachment security were those that focused on developing maternal sensitivity.

- Interventions of fewer than five sessions showed an effect on child attachment security.

- Interventions carried out with children older than six months were more successful than with younger infants.

- Sample characteristics such as age, socio-economic status, social isolation, single parenthood and child temperament were not significant moderators.

- Families who presented multiple risks (poverty, single parenthood etc.) did not require more sessions than those families with fewer risks. Similarly, the interventions were most successful at six months and older.

In conclusion, the literature demonstrates that interventions designed to promote maternal sensitivity can be successful at facilitating secure attachment for children. Furthermore, it seems that this is possible in relatively few sessions, most effectively with children at least six months of age or older. Interestingly, this type of intervention was found to be successful even in families where multiple risk factors were present.

Summary

Evidence suggests that attachment interventions can be highly successful in facilitating parent-child bonding with at-risk populations and can bring about change in relatively few sessions. It is possible, therefore, that such intervention may be used to benefit the children of parents with learning disabilities in order to promote resilience.

The next section draws the literature review together; outlining the reasons for this research.

2.5 Reasons for this research

The literature suggests that people with learning disabilities often struggle to provide adequate care for their children, due to difficulties in the parenting role (McGaw and Newman, 2005), societal discrimination with regards to their ability to do so safely (Booth, 2000) and a lack of support services to meet their needs (Tarleton *et al.*, 2006). So common is this struggle that approximately half of the children born to parents with learning disabilities are routinely removed from their care (Emerson *et al.,* 2005).

Despite their significant level of vulnerability, research into outcomes for the children of parents with learning disabilities is only just beginning (*Good practice Guidance on Working with a Parent with a Learning Disability*: Department of Health, 2007). Although five studies were identified which considered the genetic inheritance of learning disability (Accardo and Whitman, 1990; Brandon, 1957; Gillberg and Geijer-Karlsson, 1983; Reed and Anderson, 1973; Shaw and Wright, 1960), only nine were identified which investigated social, emotional psychological or behavioural outcomes for these children. While numerous methodological flaws in such studies have meant conclusions can only tentatively be drawn, they have indicated that children may be at risk of developmental difficulties (Feldman *et al.*, 1985; Feldman and Walton-Allen, 1997), maltreatment (Booth and Booth, 1997; Ronai, 1997), psychological and social problems (Gillberg and Geijer-Karlsson, 1983; McGaw *et al.,* 2007) and complexities within the parent-child relationship (Booth and Booth, 1997; Kohler and Didier, 1974; O'Neill, 1985; Perkins *et al.*, 2002).

Research has also suggested that the children of parents with learning disabilities can be vulnerable to courtesy stigma as a result of their parents' social status (Perkins *et al.*, 2002). Where children are exposed to such discrimination, there is evidence to suggest it may pose a risk to self-esteem (Wahl and Harman, 1989).

To date there has been little investigation into courtesy stigma in this population (Perkins *et al.*, 2002). No studies were found which examined children's resilience to

such adversity. The current research was therefore designed to address this gap in the literature.

It was hypothesised that courtesy stigma would impact negatively upon self-esteem. It was also hypothesised that attachment and social support may act as resilience factors, which would protect children's self-esteem from the negative effects of courtesy stigma. These resilience factors were drawn from the wider literature, which has found a child's attachment to their mother and the level of peer support they can access both act as resilience factors for children faced with risks to development (Bolger and Patterson, 2001a; Bolger *et al*., 1988; Collishaw *et al*., 2007; Kim and Cicchetti, 2004; Owens and Shaw, 2007; Schwartz, 2000).

In order to isolate courtesy stigma as a variable for investigation, the decision was taken to exclude children also at risk of primary stigma (i.e. children with a learning disability themselves). Similarly, in order to examine the role of attachment in resilience, children who were known to child protection agencies were excluded; as some may have been subject to abuse or neglect by their parents, which would indicate increased likelihood of an attachment problem (Howe, 2005). As such, their inclusion in this research could have made outcomes more difficult to ascertain.

The research questions were as follows:
- *Is there a causal relationship between high perception of stigma and lower levels of self-esteem?*
- *Is there a causal relationship between attachment problems and self-esteem?*
- *Is there a causal relationship between attachment problems and perception of stigma?*
- *Is there a causal relationship between attachment problems and low levels of social support?*
- *Do attachment problems moderate the relationship between stigma and self-esteem?*

Research into children of parents with learning disabilities has largely taken a qualitative (Booth and Booth, 1997; Kohler and Didier, 1974; O'Neill, 1985; Ronai, 1997) or audit approach (Gillberg and Geijer-Karlsson, 1983). Perhaps this is reflective of the small numbers of participants such studies are able to recruit, where qualitative methodology is particularly well placed. However, some researchers have adopted a quantitative approach and used standardised measures to assess outcomes (Feldman, *et al*., 1985; Feldman and Walton-Allen, 1997; McGaw *et al*., 2007, Perkins *et al.*, 2002), in samples ranging from twelve to fifty-eight participants.

As the current study had clearly identified research questions from the outset, that sought to examine specific relationships between variables, a quantitative approach was adopted. This allowed for distinct definitions of risk, resilience and adaptive behaviour.

The literature review identified only one published study in this area, by Booth and Booth (1997), which took a qualitative approach and did not clarify risk or define adaptive behaviour, limiting the generalisability of findings. By taking a quantitative, variable-focused approach, the current study therefore aimed to promote greater applicability of findings to the rest of the population in question.

Summary

Drawing on the literature review, a number of research questions were developed to investigate the relationships between perceived stigma, self-esteem, attachment and social support. This allowed for clear definitions of risk, resilience and adaptive behaviour, as described in the following section.

2.6 Building a model for investigation: child maternal attachment as a resilience factor to courtesy stigma in the children of parents with learning disabilities

A child's perception of stigma in relation to their mother was considered a risk to child development. Self-esteem was viewed as a measure of adaptive outcome. The main resilience factors identified for investigation were attachment and social support. Although not the main focus of this research, the role of child age, gender and level of cognitive functioning in resilience were also considered.

The model for investigation was as follows:

Courtesy stigma as a risk factor

The literature reviewed has indicted the children of parents with learning disabilities may be vulnerable to courtesy stigma (Perkins *et al.*, 2002). The experience of courtesy stigma is undesirable, due to its potentially negative impact upon self-esteem (Wahl and Harman, 1989).

Attachment and social support as resilience factors

Secure attachment to a main caregiver is well established as a core resilience factor for children facing adversity (Collishaw *et al.*, 2007; Kim and Cicchetti, 2004; Owens and Shaw, 2007). It promotes a sense of psychological coherence and self-confidence, in that one is valuable and worthy of love (Howe, 2005).

This underlying attachment style may also have a significant influence on a child's expectations of subsequent relationships (Howe, 2005). It may influence the level of social support a child seeks out from others outside the family (Sarason *et al.*, 1983).

However, where a child is able to achieve satisfactory relationships with peers and others adults, this support can act as a resilience factor in the face of negative experiences (Bolger and Patterson, 2001a; Bolger *et al.*, 1988; Schwartz *et al.*, 2000).

Self-esteem as a measure of adaptive outcome

Self-esteem is a fundamental measure of an individual's well-being (Emler, 2001). It has been used by numerous resilience studies as a measure of adaptation in the face of risk (e.g. Luthar, Cicchetti and Becker, 2000).

Summary

In summary, attachment was conceptualised as a resilience factor, which may protect self-esteem from the risks posed by courtesy stigma for the children of parents with learning disabilities.

The next section describes the path analysis model, which was developed in order to examine the causal nature of relationships between variables in a unified manner.

Chapter 3: methodology

3.1 Study design: path analysis

Path analysis was used to build a model of the relationships between perception of stigma, levels of self-esteem, attachment-related problems and the degree of social support for children of parents with learning disabilities. This allowed the researcher to examine the nature of these relationships in one unified analysis and consider causation between variables.

Schumacker and Lomax (1996) provide an explanation of the design and function of path analysis. Originally developed by Sewall Wright (1934; 1954; 1960a), it is a method for examining the direct and indirect effects of a group of variables. The theoretical relationships between which are tested using Pearson product-moment correlation coefficient and regression (Wolfle, 1977). These relationships are derived from theory and evidence; the aim is to shed light on the tenability of the model.

As Kerlinger and Pedhazur (1973) explain, a distinction is made between exogenous and endogenous variables.

The variability within an exogenous variable is considered to be affected by factors that are outside of the path analysis model. The variability of exogenous variables is therefore not explained, nor are the relationships between exogenous variables.

With an endogenous variable, variation is explained by the path analysis model proposed.

Relationships between exogenous variables are shown by a curved line with arrowheads at both ends, indicating neither variable is seen as the cause of the other.

The relationships between endogenous variables are depicted by unidirectional arrows; which point in the direction of the proposed causal relationship. It is therefore the endogenous variables that were the focus of this research.

Within path analysis, the causal relationship is not seen to account for the total variance of any one variable, but rather is an estimation of the effect of one variable upon another.
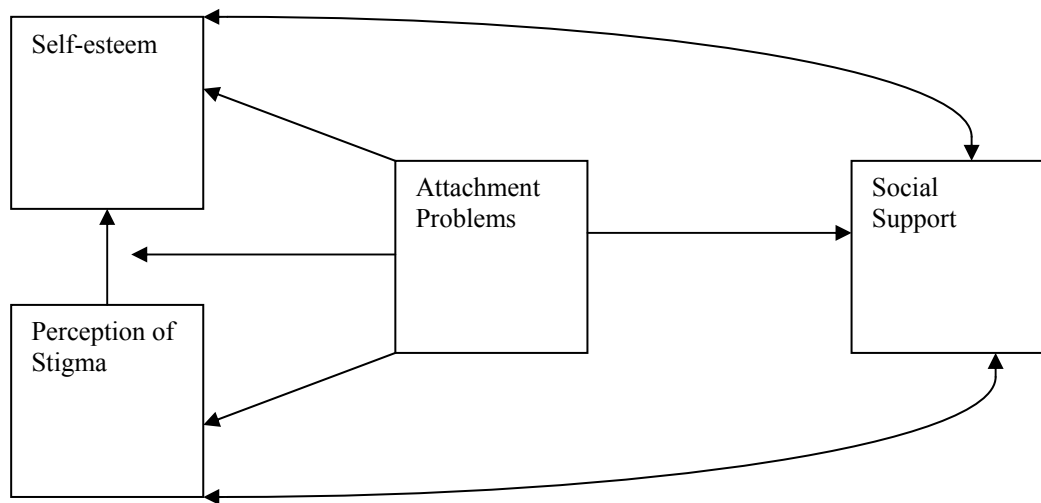
Figure 1: Path analysis model of proposed relationships among variables

In Figure 1, the correlations between exogenous variables (self-esteem and social support; perception of stigma and social support) are depicted by a curved line with arrowheads at both ends, indicating the researcher does not conceive of one variable being the cause of the other. These relationships are therefore not examined.

The correlations between endogenous variables are depicted by unidirectional arrows and are therefore considered to be causal paths. This model proposed that perception of stigma had a causal relationship with self-esteem. It also proposed that attachment-related problems had a causal relationship with levels of social support, as well as with self-esteem and perception of stigma.

The model posed the following research questions:

- **Research question a**

  Is there a causal relationship between high perception of stigma and lower levels of self-esteem?

- **Research question b**

  Is there a causal relationship between attachment problems and self-esteem?

- **Research question c**

  Is there a causal relationship between attachment problems and perception of stigma?

- **Research question d**

  Is there a causal relationship between attachment problems and low levels of social support?

- **Research question e**

  Do attachment problems moderate the relationship between stigma and self-esteem?

Summary

The path analysis model allowed for examination of the relationships amongst variables. However, research with the children of parents with learning disabilities generally involves small numbers of participants which raises some statistical complexities in the context of quantitative research. The next section discusses these issues.

3.2 Power, effect and sample size

Sample size and research with children of parents with learning disabilities

McGaw (1997) estimated there to be around 250,000 parents with learning disabilities known to health and social services in the United Kingdom. Although this figure included parents whose children had been removed into care as well as those still residing at home with their parents, it gives an indication as to the existing number of children of parents with learning disabilities in the population as a whole.

Many of these children are taken into care at a young age, so those who remain with their parents are a particularly select group. Those who remain with their parents and yet are not monitored under child protection are an even smaller group.

Very little research to date has focused on the children of parents with learning disabilities, as previously discussed. This may, in part, be due to the methodological difficulties generated by the small sample sizes involved. To date, researchers in this field in the United States, Australia and the United Kingdom have recruited samples that range between n = 5 (Kohler and Didier, 1974) and n = 58 (McGaw *et al*., 2007), using qualitative and quantitative methodologies.

A study in this area necessarily involves small samples, but this should not deter psychologists from examining the needs of this vulnerable group of children. In this respect, comparisons can be made between research in this population and in areas such as brain damage, where small sample size is also typical (e.g. Harris *et al*., 2002).

Sample size and effect

This study recruited n = 24 participants. In order to protect against Type I and Type II errors when reporting research findings, a post-hoc power analysis was carried out on each of the regression analyses for the research questions. This was done using Soper's (2007) statistical power calculator.

It is possible for small sample size research to have low statistical significance while still finding large effect. The larger the effect size in a study, the greater the power.

The correlation coefficient itself is a measure of effect size. Traditionally, Cohen's (1988) conventions are used when thinking about correlation size. A large correlation is considered to be .50 or above, a moderate correlation .30 and a small correlation .10.

However, the square of the correlation r^2 is more commonly used, which is known as the coefficient of determination. As Kinnear and Gray (2007) describe, the square of the Pearson correlation is 'the proportion of the variance of the scores on the target or criterion variable that is accounted for by regression upon another variable'.

Effect size of r^2 can be classified as follows (Kinnear and Gray 2007):

Effect size (r^2)	Size of effect
<0.01 (<1%)	Small
0.01 to 0.10 (1-10%)	Medium
>0.10 (>10%)	Large

One-tailed or two-tailed testing

A one-tailed test is a procedure for looking at the direction of a research hypothesis, where the region of the comparison distribution is all on one side, or tail, of the distribution.

A two-tailed test is for non-directional hypothesis testing, where the region of the comparison distribution is divided between the two sides or tails of the distribution.

Using a two-tailed test makes it more difficult to gain significance on any one tail – a one-tailed test is likely to increase power where a two-tailed test decreases power (Aron and Aron, 2002).

In this research, the evidence base from which the variables were drawn suggested directional relationships - between perception of stigma and self-esteem, attachment and self-esteem, attachment and perception of stigma and attachment and social support. Consequently a one-tailed test was used.

Statistical significance and significance level

A result is considered significant if it is unlikely to have occurred by chance.

The significance level of a test is defined as the probability of rejecting the null hypothesis when the null hypothesis is actually true, known as a Type I error or alpha (α). This decision is made using the p-value: if the p-value is less than the significance level, then the null hypothesis can be rejected.

A Type I error can be made if the study supports the research hypothesis when in reality it is false. More extreme levels of significance, such as .01 and .001, protect against making a Type I error. However, while protecting against this risk, it may also be the case that in reality the research hypothesis is actually true, but statistically the result is not at a threshold to reject the null hypothesis.

If the results of a study are reported as inconclusive when in fact the research hypothesis is true, it is called a Type II error or beta (β). To reduce the probability of making a Type II error, it is possible to set a more lenient significance level, such as $p < .10$ or even $p < .20$.

Therefore, protecting against one kind of error increases the risk of the alternative error. The compromise is normally found by selecting the .05 and .01 significance levels (Aron and Aron, 2002).

Yet, with correlations, a small sample size increases the risk of finding statistical significance by chance, increasing the likelihood of Type I error.

To reduce the risk of Type I error in this research, the results were checked against Miles and Shevlin's (2007) statistical table of critical values for Pearson's r. This table provides the significance levels for Pearson's correlation using different sample sizes.

While researching an area like children of parents with learning disabilities will often involve small sample sizes, it is also the case that precautions can be taken to reduce risk of making false claims about the data.

Consequently, this research established effect sizes between variables under investigation, as well as considered p values.

Nonetheless, even where reliable findings were evident, the sample size involved means that generalisability to the wider population of these children should be treated with caution.

Summary

In summary, research into the children of parents with learning disabilities typically involves small numbers of participants. In this respect, comparisons can be made between research in this area and in fields such as brain damage, where small sample sizes are also the norm.

A difficulty with small sample size is that it can lead to Type I errors. In this research, effect size was considered a more reliable indicator of the strength of relationships between variables than statistical significance.

One-tailed testing was chosen, as the suggested relationships proposed in the path analysis model were casual and thus unidirectional.

The next section now turns to the wider development of this research, for which a reference group was established. This reference group provided guidance on several aspects of this study from its inception to conclusion.

3.3 Research reference group

A research reference group was established to provide advice and guidance with regards to the design of the study at its initial conception and then to provide comment on the research findings. It consisted of experienced, qualified social workers and consultant psychologists from the child and adolescent mental health service, child social services, adult learning disability social services, adult learning disability health services and the children's charity Barnardo's, as well as a service user – a mother with learning disabilities.

Although the reference group only formally met twice throughout the duration of the study, members of the group were colleagues with whom the researcher was in frequent contact. As such, they were aware of the progress of the research on an ongoing basis.

The first meeting was held in September 2004, where the reference group were presented with the research idea and aims. The process of gaining ethical approval was discussed, as was the issue of identifying potential participants.

During this first meeting, the group commented on the content of the draft research protocol, giving suggestions as to how to improve the study design. They reviewed associated documents that would be piloted and submitted to ethics, such as the research participant information leaflets (which described the study and invited people to participate) and the mother and child consent forms. Finally, they evaluated the formal measures that were used with children to assess perception of stigma, self-esteem, social support and attachment.

A second meeting was held in June 2007, at the point when the research data had been collated and initial analysis carried out. Members commented on the findings of the research and their significance in relation to current clinical practice.

The reference group was in agreement that interventions designed to promote good attachment were likely to encourage resilience to stigmatisation for these children. In addition, they felt future research needed to take into account attachment to father as well as co-morbid problems for the mother – such as mental health problems.

Lastly, the reference group commented on content and the design and layout of the research feedback summary, which was sent out to each mother and child who had participated in the study.

Summary

The reference group helped develop the research, commenting on different aspects of the study.

The next section details this researcher's submission to MREC, which culminated in ethical approval for the study to take place.

3.4 Multi-centre Research Ethics Committee (MREC) approval

In January 2005, the research proposal and supporting documents were submitted to Metropolitan MREC for ethical approval. The researcher was invited to attend the ethics review meeting in order to answer questions about the study. The feedback was positive from the committee, but they had two main areas of concern.

First, they disagreed with the researcher's original proposal to assess mothers for learning disabilities on the basis of professional opinion and their being in receipt of specialist services: the social systems definition (Mercer, 1973). They advised that, instead, mothers must be assessed formally for learning disability using DSM-IV diagnostic criteria (American Psychiatric Association, 1999). The MREC panel argued using this criteria would ensure all mothers had a cognitive impairment as well as adaptive behaviour deficits. They felt that the social systems definition would leave room for sampling error, as technically some parents could be considered by professionals as having a learning disability, although they may simply be low functioning for other reasons, such as mental health problems.

Similarly, the original research proposal had intended to assess children for the absence of learning disability on the basis of their attendance at a mainstream school. Instead, MREC requested children be assessed using psychometric measures to formally establish this was the case.

Second, they were also concerned that the language used in the research questionnaires and information leaflets was not going to be understood by the younger children. They therefore requested a pilot study be carried out to ensure age-appropriate language was used on all documentation.

Therefore, *conditional* approval was given in February 2005, on the basis these two amends were carried out.

As a result, the researcher revised the study design and included psychometric measures to assess for learning disability with mothers, and rule out the existence of learning disability in children.

The researcher then carried out a pilot study of all the research questionnaires and information leaflets. This was conducted with three groups of school children to ensure that age-appropriate language was used on all forms. A similar pilot study was carried out with mothers.

The details of these pilot studies are given below.

Pilot of information leaflets and consent forms for parents with learning disabilities

The research information leaflet was shown to a group of five learning disabled mothers in a South Gloucestershire Learning Disabilities Team. Mothers were considered to be representative of their population. They ranged in age from 17 to 36 years old.

Each mother was given a leaflet describing the research. They commented on the design, language and content of the leaflets to ensure ease of accessibility.

The leaflets for mothers with learning disabilities were designed in conjunction with MENCAP's guidance on accessible writing (MENCAP, 2002). Change Picture Bank symbols were used to aid understanding (www.changepeople.co.uk). Following the initial pilot, amendments were made and the leaflets were piloted again.

The final version was then prepared and submitted to ethics for approval.

Pilot of research information leaflets, consent forms and measures for children

The questionnaires and leaflets were piloted with children to ensure age-appropriate language.

In line with 'Guidance on Ethical issues in Research in Children' (COREC, 2003) and 'Guidance on Ethical Issues in Research in Children' (COREC, 2003), the children involved in the piloting process were broken into three groups: 8-12 years old, 13-15 years old and 16-17 years old.

A primary school in South Gloucestershire was contacted and the study explained to the headmistress over the telephone. A leaflet explaining the research was sent to the headmistress, along with draft research information leaflets and questionnaires to be piloted. The headmistress then discussed the project with her staff and the researcher was invited into the school to answer any questions raised by the teachers.

Once this had been completed, the researcher arranged with a form teacher to meet with 10 children between the ages of 8 and 11 years old. The children selected for the group were of mixed ability, although no child had any specific learning disability. The school designated an empty classroom and the children sat round a table with the researcher for approximately one hour, with a break in the middle.

The children were first given the research questionnaires - Perception of Stigma Scale, Rosenberg Self-esteem Scale, Social Support Questionnaire and Adolescent Attachment Questionnaire - to read.

They were then given the research information leaflets designed for children aged 8-12 years old.

They were given coloured marker pens and each highlighted a word if they did not understand it. The researcher then collected the forms and created a list of unknown words. The researcher went through each word, explaining its meaning, and asked children for alternative words or ways of phrasing a sentence.

For example, the first question on the Social Support Questionnaire short form (SSQ6) reads, 'Who can you count on to be dependable when you need help?' Children requested this be changed to 'Who can you really count on when you need help?' Several amendments were made to the questionnaires, but the research information leaflet for 8-12 year olds needed no amendment.

This pilot was then carried out with adolescents at a secondary school in Bristol. A similar process was followed, wherein the researcher contacted the headmaster of the school and explained the research aims and design. The headmaster then put the researcher in contact with a liaison teacher who organised for 12 young people between the ages of 12 and 16 years old to meet with the researcher over a lunch period.

The four amended questionnaires were shown to them, along with the research information leaflets for children 13-15 years and 16-17 years.

As before, the children were asked to highlight any words they were not sure of. However, no further amendments were needed.

Summary

MREC requested two amendments be made to the original research proposal in order to grant ethical approval.

The first was that learning disability should be established (with mothers) or ruled out (with children) using psychometric measures. The second was that all questionnaires and research information leaflets were piloted with children to ensure age-appropriate language.

These requests were carried out and final copies of the questionnaires and information leaflets were prepared and submitted to MREC for final approval in August 2005.

In September 2005 full MREC approval was given and the main research began.

The next section considers the issue of consent to participate in research for both children and mothers.

(See appendices A-D for research information leaflets)

3.5 Consent and risk assessment

In this research, consent was required from learning disabled mothers for their children under sixteen years old to participate. It was considered important that the mother gave consent as opposed to the father, as this research had the primary aim of investigating aspects of the mother-child relationship.

However, the information leaflet for mothers was also given to fathers if they lived at the same address. If parents were separated, then, where possible, the father was sent an information leaflet with a covering letter explaining the research.

Capacity to consent is an issue regularly raised in connection with people who have learning disabilities. Whether a person is learning disabled or not, individuals have a fundamental and legal right to self-determination (British Medical Association and The Law Society, 1995).

Adults are always presumed to have the capacity to consent unless the opposite has been demonstrated. This applies just as much to mothers with learning disabilities as to any other adult (*Valuing People*: Department of Health, 2001).

Three conditions must be met for consent to be valid:

- The person must be capable of taking that particular decision or 'competent'

- The person must be acting voluntarily

- The person must be provided with enough information to enable them to make that decision. Mothers identified in this research met these three conditions for the following reasons:
  1. Those identified were in the upper end of the mild learning disability range (IQ 60-70). They were also living independently with their child and were making choices about their own and their child's needs on a

daily basis. Consequently, mothers would have possessed the cognitive ability to understand the nature and meaning of the research.

2. It was made clear to mothers by the person who initially contacted them, and by the researcher, that their children were under no obligation to take part and were free to withdraw from the study at any stage. The information leaflets also stated this.

3. In addition to the information leaflets, the researcher discussed the study with mothers in detail before they decided whether or not they agreed for their child to take part.

Thus, the requirements were met for these learning disabled parents to be able to give, or withhold, their consent for their child's participation.

In the eyes of the law, young people aged sixteen to seventeen years old are able to consent for themselves (COREC, 2003) and were therefore asked to sign an individual consent form.

Children aged thirteen to fifteen years old were required to give their individual assent to participation. Their mother was involved in the decision making process and gave their consent. Child assent and maternal consent were recorded on *separate* forms.

Children aged eight to twelve years old gave their assent to participation in the research, as did their mothers. In this younger age group, child assent and maternal consent were recorded on the *same* form.

Where a mother was clearly unable to understand the nature and meaning of the research, the children were not invited to participate.

Similarly, where a child was considered competent to participate but the mother was unwilling for them to be involved, the child was not included in the research. This was to avoid creating conflict between mother and child (and potentially guilt in the

child), as there would have been no ongoing or lasting benefit to them in participating in the research.

Before the study commenced, two risks to participants were identified:

- The first was that the questions asked during interview may have evoked emotional responses for the children or young people. In this event, the interview would have ceased, initially for a short break in order to establish what was causing the upset.

  Where necessary, the interview would have been terminated and the participant offered a debrief session. The aim of this debrief would have been to provide initial support and comfort and to further establish the nature of the participant's distress. Where necessary, the researcher could have sign-posted, or made a direct referral to, services.

- The second identified risk was the raw data collected during the interview may have indicated a heightened need. For example, if a child reported significantly low self-esteem.

  As above, the researcher could have sign-posted appropriate strategies or made a referral to services if necessary.

Fortunately, none of the above risks arose during the process of the research.

(See appendices E – I for consent and assent forms for all participants)

Summary

Once MREC approval had been gained, and consent and risk assessment had been clarified, the study was able to commence. The next section provides detail on the test measures used to examine the variables of IQ, adaptive behaviour, self-esteem, perception of stigma, attachment and social support.

3.6 Measures

Mothers included in this study were assessed for a learning disability using the Wechsler Abbreviated Scale of Intelligence (WASI) (Weschler, 1999) and the Adaptive Behaviour Assessment System - II (ABAS –II) (Harrison and Oakland, 2000).

Children in the study were assessed using the same instruments to ensure they did *not* have a learning disability. In addition, children were also administered the:

- Rosenberg Self-esteem Scale (Rosenberg, 1965)
- Perception of Stigma Questionnaire (Perkins *et al.,* 2002)
- Adolescent Attachment Questionnaire (West *et al.,* 1998)
- Social Support Questionnaire – short form (Sarason *et al.,* 1987)

(see appendices J to O for test measures)

These measures were administered in two formal meetings with the researcher.

Wechsler Abbreviated Scale of Intelligence (WASI) (Weschler, 1999)

The WASI, an individual measure of intelligence, was carried out with mothers and children. The researcher had received training in the administration and interpretation of this test.

The WASI has a ten point measurement of error; a result of which mothers with IQ up to 75 were included in the research.

The WASI contains four subscales – Vocabulary, Block Design, Matrix Reasoning and Similarities. These subscales are similar in design to the original Wechsler Adult Intelligence Scale – Third Edition (WAIS-III) subscales and together yield an overall IQ.

This test can be administered using either the four subscales, which take 30 minutes to complete, or the two subscales, which take 15 minutes to complete.

For the purposes of this research, the two subscale test was administered, comprising only the Vocabulary and Block Design subtests. This provided a full-scale IQ score.

The reliability coefficient for the WASI Full Scale IQ is .96 - .98 (Weschler, 1999).

Adaptive Behaviour Assessment System-II (Harrison and Oakland, 2000)

Before selecting this instrument, questionnaires that measure adaptive behaviour were reviewed. There are many, of which a significant number hold good psychometric properties.

The ABAS-II was chosen, as it is a comprehensive norm-referenced assessment of the adaptive skills of individuals from birth to eighty-nine years old. The ABAS–II can be used to diagnose and classify disabilities and disorders.

It comprehensively assesses all ten areas of adaptive behaviours specified by DSM-IV in relation to learning disabilities. It is also able to be used with non-learning disabled populations.

A rating form is administered to the individual or to a significant other. The rating form comprises one hundred and ninety-three items and can be completed by a respondent in approximately 20 minutes. The instructions and items can be read aloud to a respondent if he or she does not have the necessary reading skills to complete the form independently.

The rating scale for the ABAS–II items requires a respondent to indicate if the individual being assessed is able to perform an activity independently and, if so, how frequently (always, sometimes, or never) he or she performs it.

The ABAS-II has been found to demonstrate high internal consistency. Reliability coefficients for the adaptive domains range from .91 to .98. Average reliability coefficients of the skill areas across age groups are typically in the .90s, ranging from .85 to .97 (Harrison and Oakland, 2000).

Self-esteem Scale (Rosenberg, 1965)

Self-esteem measures were reviewed for this research. The Rosenberg's Self-esteem Scale (Rosenberg, 1965) was selected to measure self-esteem in this study, as it is a well utilised measure, originally developed to measure adolescents' global feelings of self-worth. It is generally considered the gold standard against which other measures of self-esteem are compared (Emler, 2001). This tool has been used extensively in research with children and adolescents.

The measure takes approximately 5 minutes to complete. It comprises of 10 items that are scored using a four point response, ranging from strongly agree to strongly disagree. Possible scores on this instrument range from 10-40, with high scores indicating greater levels of self-esteem.

Blascovich and Tomaka (1993) report test-retest correlations in the range of 0.82 to 0.88 and Cronbach's alpha in the range of 0.77 to 0.88.

Perception of Stigma Questionnaire (Perkins *et al.*, 2002)

To date, the assessment of courtesy stigma has mostly focused on adult populations. It has been investigated using either a qualitative interview approach, or questionnaires, with items drawn from the literature on stigma (Birenbaum, 1970; 1992; Corrigan *et al.*, 2006; Norvilitis *et al.*, 2000). No standardised measures were identified, which considered courtesy stigma in adults.

Studies which have investigated courtesy stigma for children have also taken a qualitative approach; no standardised assessments were found. Investigations have mostly used case vignettes, giving examples of children with a parent who has mental

health or drug and alcohol problem, shown to non-stigmatised adolescents and college students (Burk and Sher, 1990; Mehta and Farina, 1988). This research has established that children with a discredited parent are at risk of stigma by association. However, no studies were found which assessed courtesy stigma from the perspective of the stigmatised child (Link *et al*., 2004), with the exception of Perkins *et al.* (2002).

Perkins *et al.* (2002) developed a six item measure called the Perception of Stigma Questionnaire, which they used with the children of parents with learning disabilities. The authors explain that items in the measure were drawn from the literature, which suggests courtesy stigma is most acutely experienced in the context of social interactions (Dudley, 1997; Goffman, 1963; Sabsay and Platt, 1985). Cronbach's alpha for the Perception of Stigma Questionnaire has been found to be 0.7 (moderate internal consistency) (Perkins *et al.,* 2002). The Perception of Stigma Questionnaire was considered to be a 'best fit', in order to measure courtesy stigma in the current study. Using this measure brought the additional benefit of being able to compare the outcomes for children in the current research, with those reported by Perkins *et al.* (2002).

The Perception of Stigma Questionnaire measures *perceived* courtesy stigma, rather than actual discriminatory experiences. Research has identified that individuals may have a high perception of courtesy stigma, even in the absence of prejudicial acts by others (Corrigan *et al.*, 2006; Wahl and Harman, 1980). High perceived stigma leads to 'self-stigma'; an internalised stigmatised view of the self, which arises out of being associated with a discredited family member (Corrigan *et al*., 2002).

Perceived courtesy stigma was therefore the focus of the current study. All of the mothers who took part were known to services due to their learning disability, and were therefore at increased risk of discrimination as a result of their social status (Beart *et al.,* 2005). Consequently their children were vulnerable to courtesy stigma, as a result of their beliefs about how others view them, and their own internalised self-stigma.

The Perception of Stigma Questionnaire (Perkins *et al.,* 2002) takes approximately 5 minutes to administer and assesses issues such as the extent to which the child feels

confident to go on public outings with their mother and the extent to which the child feels comfortable having their friends around their mother. Each item has three anchor points: (0) a lot, (1) sometimes and (2) never. A sample item is 'How comfortable are you if your friends talk to your mother?' Answers are summed to create a single scaled score representing the degree of stigmatisation. Possible scores on this instrument range from 0-12, with higher scores indicating perceptions of greater stigmatisation.

Dr Vietze from the New York State Institute for Basic Research in Developmental Disabilities, one of the team who conducted the Perkins *et al.* (2002) study, kindly gave his permission for their unpublished Perception of Stigma Questionnaire to be used in this research.

However, in carrying out this investigation, several difficulties were noted with the Perception of Stigma Questionnaire, which raised issues about the validity of the scale. These are explored in detail in the section 5.5 of this thesis.

Adolescent Attachment Questionnaire (West *et al.*, 1998)

Attachment measures were reviewed for the purposes of this research. This is a complex area; there are many attachment measures, with different categories evaluating different phenomena. The crucial two questions a researcher needs to ask themselves with regards to attachment measures are a) What is the attachment relationship under scrutiny? and b) What is the age group of the population being studied?

For the purposes of this research, the Adolescent Attachment Questionnaire (AAQ), designed by (West *et al.*, 1998), was considered to be a 'best fit'. This is a brief questionnaire that assesses attachment characteristics in children and takes approximately 10 minutes to complete.

It consists of three scales of three statements each; one scale measures Angry Distress (AAQ Angry Distress), one Availability (AAQ Availability) and one Goal Corrected Partnership (AAQ Goal Corrected Partnership).

- The AAQ 'Availability' scale assesses the extent to which the adolescent has confidence in the attachment figure as 'reliably accessible and responsive to most of his/her attachment needs'.

- The AAQ 'Angry Distress' scale taps negative responses to the perceived unavailability of the attachment figure.

- The AAQ 'Goal Corrected Partnership' scale assesses the extent to which the child considers and has empathy for their primary attachment figure.

These scales can be viewed together (AAQ Full Score) to give an overall assessment of the child's perception of their attachment figure. Alternatively, specific issues within the attachment relationship can be tapped by viewing the scales independently.

It scores using Likert-type responses ranging from strongly disagree to strongly agree. Possible scores on each of the three scales range from 3 -12, with higher scores on each of the three scales indicating greater problems with that dimension.

The AAQ has been shown to have Cronbach's alpha of 0.80, indicating a high degree of internal consistency (West *et al.*, 1998). Test-retest correlations showed high temporal stability for all 3 scales (West *et al.*, 1998).

The AAQ has also demonstrated strong convergent validity with the Adult Attachment Interview (AAI) (Main, 1985), which is considered to be the gold standard for adult attachment measurement (Cassidy and Shaver, 1999) and the most commonly used classification of attachment in later age periods. The AAI has a three category system, with individuals scoring secure, dismissing or preoccupied with their attachment relationship.

Using a sample of one hundred and thirty-three adolescents, West *et al.* (1998) compared results on the AAQ with results on the AAI. Adolescents who were classified as secure according to the AAI reported more 'Availability' of their attachment figure. Those who were classified as dismissing of attachment on the AAI reported less 'Goal Corrected Partnership'. Those classified as preoccupied on the AAI reported more 'Angry Distress'.

However, although the AAQ scales relate in a meaningful way to the traditional three category AAI classification system, it would be incorrect to regard the scales as directly measuring the same attachment categories.

Attachment status derived from the AAI interview is fundamentally based on assessment of unconscious defensive processes. Self-report methodology cannot tap this dimension and, therefore, cannot be used to give a firm index of the categories of attachment in the same way as the AAI.

Nonetheless, the AAQ can reliably be regarded as assessing adolescents' perceptions of the available responsiveness of their attachment figure and these findings can in turn be discussed in light of the strong convergent validity with the AAI categories.

Social Support Questionnaire – short form (Sarason *et al.,* 1987)

Measures that evaluate the level and quality of a child's social support were reviewed. As with attachment measures, the study of social support as a concept has generated a large amount of research and there are many measures from which to choose. The Social Support Questionnaire – Short Form (SSQ6; Sarason *et al.,* 1987) was selected as it was based in part on Bowlby's theory of attachment and, as such, ties in with same concepts measured by the AAQ.

The SSQ6 is a six-item questionnaire, which yields scores for the perceived number of supports and satisfaction with social support that is available. It has been used extensively in research with children and adolescents. It takes approximately 15 minutes to administer. Respondents are asked to list nine potential support providers

in hypothetical situations, such as 'whom can you really count on to listen when you need to talk?' Respondents then rate their overall satisfaction with support for each situation rather than each provider.

The children in this study were specifically asked to list peer relationships and other friendships outside of the family. Where children were unable to identify nine friendships, they were asked to list supportive others from within the family network. This included fathers and mothers' boyfriend.

The SSQ6 yields a total score for number of supporters (SSQ6n) and support satisfaction (SSQ6s). Possible scores on this instrument range from 0-9 for SSQ6n and 1-6 for SSQ6s, with higher scores equalling higher levels of satisfaction. Internal reliabilities for the SSQ6 are reported as ranging from 0.93 to 0.96 and the Cronbach's alpha 0.71 (Sarason *et al.,* 1987).

Summary

The WASI (Weschler, 1999) and the ABAS-II (Harrison and Oakland, 2000) were used either to assess for learning disability in mothers or to rule out learning disability in children.

All children who participated in the study were also administered the Self-esteem Scale, Perception of Stigma Questionnaire, Adolescent Attachment Questionnaire and the Social Support Questionnaire.

The next section now turns to the research inclusion criteria for mothers and children who participated in the study.

3.7 Research inclusion criteria for participants

Mothers

The inclusion criteria for this study were mothers with a learning disability who acted as the main carer for their child. Caregiver status was established by the researcher asking staff who knew each respective mother well and who were therefore in a position to advise upon the family arrangements.

Mothers were required to have a learning disability as assessed by the WASI (Weschler, 1999) and the ABAS-II (Harrison and Oakland, 1999). Mothers with IQ up to 75 were included, due to the ten point measurement of error on the WASI. These measures were administered to every mother except one, who had recently undergone a full assessment of IQ and adaptive functioning. In this instance the researcher was able to use this data rather than ask the mother to repeat the process.

Mothers were already aware of their learning disability; however, only one had evidence of previous IQ or adaptive behaviour testing. Mothers were therefore generous in accommodating the researcher's request to formally assess their learning disability again, in order to ensure the integrity of research data. Consequently, it was not considered necessary to feed back their psychometric data; in fact, it seemed more sensitive not to do so. It was not notifying them of new information and may have brought the uncomfortable issue of their 'deficits' to their attention unnecessarily. No mothers requested these results themselves.

It was interesting to note that mothers who came forward to participate in this research were all white British. This raised questions about the extent to which learning disabled mothers from ethnic minority groups were known to services in this study. Indeed, this observation is reflected in the literature, which demonstrates very little investigation to date into parents with learning disabilities from such communities (O'Hara and Martin, 2003).

Children

Criteria for inclusion was an age range of 8-17 years, male or female, with no identified learning disability and living with mother who was the primary caregiver.

The minimum age of 8 years old was necessary in order to ensure that the measures used were age-appropriate. The maximum age was 17 years, as most children had moved on from their mother as their primary attachment by this age.

The absence of learning disability in children was established again using the WASI (Weschler, 1999) and the ABAS-II (Harrison and Oakland, 2000). All children who participated had an IQ of above 75. As the measures had been used as a screening tool and were not the main focus of the investigation, no specific information about IQ was fed back to the children after assessment, other than to confirm they did not have a learning disability.

Children with learning disabilities were excluded to control the number of variables under examination. Children with learning disabilities themselves may have been vulnerable to primary stigma (as a result of their learning disabled status), in addition to courtesy stigma. As this study focused specifically upon courtesy stigma, children at risk of primary stigma were excluded.

Children subject to child protection were also excluded. Again, this was to control for the number of variables under examination. Children registered with child protection may have, in some cases, been subject to a level of neglect and/or abuse by their mother, which could directly impact upon the quality of mother-child attachment. Including such children could have confounded the results of this research, as (even though the mother may still be the child's main carer), attachment may already be disrupted. As this research aimed to provide a baseline, and establish if secure attachment could act as a resilience factor to courtesy stigma, children monitored under child protection plans were therefore not included in the study.

Summary

The inclusion criteria were mothers with a learning disability, who were acting as the main carers for their children.

The criteria for a child's inclusion were: no identified learning disability, aged between 8 and 17 years old, and not subject to child protection at the time of the investigation.

The next section details the process carried out to identify the population of mothers and children who participated in this research.

3.8 Service survey for potential participants

Recruiting participants to this study was a complex process. The researcher therefore allowed eighteen months solely for this part of the project. The process was begun by networking within the field of parents with learning disabilities and making initial enquiries by telephone contact.

In order to identify as many children as possible, it was necessary to survey a large number of services across the country.

Once potential participants had been identified in a particular geographical area, the study was registered with the appropriate NHS Trust and their Research and Development Department.

In total, the study was registered with:
- North Tyneside NHS Primary Care Trust
- Bristol South and West NHS Primary Care Trust
- South Gloucestershire NHS Primary Care Trust
- North Somerset NHS Primary Care Trust
- Bath and North East Somerset NHS Primary Care Trust
- Cornwall Partnership Trust
- Devon Partnership Trust
- Oxfordshire Learning Disabilities Trust
- South West London and St Georges NHS Mental Health Trust.

In addition, the following voluntary agencies were also surveyed via telephone contact with service managers:
- Elfreida Society (London)
- The Greenwich Parenting Project (London)
- Options for Life Parenting Project (Birmingham)
- Circles Network (Bristol and Cardiff)

Identifying the sample via services

The first services to participate were the children's social services and adult learning disabilities teams in Bristol, South Gloucestershire and North Somerset. The researcher had contacts in these areas of the country, which made it possible to effectively network with all the relevant professionals who were working with parents with learning disabilities at that time. In total, seven participants took part from this geographical area.

Further networking identified a service for parents with learning disabilities in Exeter, Devon. However, the majority of families in this service had children under the age of five years old or were registered with child protection agencies, which excluded them from the study. Nonetheless, three potential participants were identified. One of these families took part in the project.

Two families were identified from the child learning disability team in Bath, Somerset and both agreed to participate. Again, several more children were known to this service, but were monitored under child protection and were therefore excluded from the study.

Six families met the research inclusion criteria at the parenting service for people with learning disabilities in North Tyneside. However, only one of these families agreed to actually take part. As above, other families were known to this team, but the children were monitored under child protection plans, and so were excluded from participation.

Participants were identified at the Special Parenting Service in Cornwall. This agency was established in 1988 and therefore has long-standing relationships with parents in the area. Eleven mothers and children took part from right across the county – from Penzance, Redruth, Truro, Falmouth, Hayle, Camborne, Pool, St Austell and Tresillian.

Interestingly, this Cornwall service was working with the largest number of children who were not registered with child protection agencies.

The Elfrieda Society in London works with a large group of parents with learning disabilities. The researcher had several telephone conversations with the manager of this service to discuss the study and invite members of the group to participate. This contact led the researcher to believe that there were ten people who would have met this study's criteria. However, these mothers refused to take part and even declined several offers simply for the researcher to go and talk to them.

In south London, a charity named Generate offers services to parents with learning disabilities. They invited the researcher to go and meet with them to explain the study and hand out leaflets. There were three mothers and their children who met the research criteria; one agreed to participate in the study.

Finally, one participant was identified from a parenting service in the Midlands, run by a charity called Options for Life. This mother and daughter took part in the study.

In total, forty-three families were identified who met the research criteria and twenty-four gave consent to take part in the project. Across the country, it seemed that parents' reluctance to participate in this research was a genuine fear of professional assessment, despite the researcher's repeated assurance that the research data was confidential. This was particularly the case with the Elfreida Society in London, who would not even consider discussing the project with the researcher. Quite possibly this reflected parents' general mistrust of professionals. Indeed, this issue is highlighted in the literature; a parents' fear of having their children removed has been shown to prevent them from cooperating freely with services and professionals (Booth, 2000; *Best Practice Guidance on Working with a Parent with a Learning Disability*: Department of Health, 2007).

Summary

In conclusion, networking proved successful. Areas of the country where the researcher had personal contacts, such as Cornwall and Bristol, yielded the largest numbers of participants. It was disappointing to note that there were forty-three

families that could potentially have taken part, but to have secured participation from twenty-four was more than half of the identified population.

This country-wide survey indicated that the majority of children known to services were under the age of five years old. This raised questions as to the whereabouts of older children. Knowing that approximately 50% are routinely removed into care (Booth *et al.,* 2005), the researcher was left unsure whether this survey did indeed indicate that, past the age of five years old, these children were more likely to be removed. Alternatively, of course, it may be that mothers with older children were simply no longer in need of services and were therefore not identified by this study.

Age aside, it appeared that a significant majority of children were registered with child protection agencies. This either suggested mass parenting failure on the part of people with learning disabilities or that the presence of a learning disability was in itself being considered a substantial enough risk factor, resulting in children being monitored under child protection.

However, the opposite was true in Cornwall. The Special Parenting Service in Truro had the largest population of parents with learning disabilities known to them, whose children were not being monitored under child protection plans. It seemed likely that this was due to the nature of this service, as parents in this location receive long-term support, increasing the likelihood of successful outcomes.

The next section details the procedure that was followed, to administer the research measures.

3.9 Procedure

All potential participants were identified through networking, telephoning contacts and cold calling relevant agencies.

Once local NHS Trust approval was granted for each geographical area in which participants lived, the researcher again contacted those services that had agreed to take part in the research.

The team manager was asked to approach the identified mothers and their children and to make initial enquiries as to whether they would like participate. The manager was given the information leaflets describing the study and was asked to give them to the mothers and children.

Where initial agreement and consent/assent was given to the manager by the 16-17 year olds or (in the case of younger children) by both mother and child, the contact details for those individuals were passed to the researcher.

Subsequently, the researcher requested some basic information about the family, such as how many children were in the family and whether there was a husband or partner in the home.

The researcher then arranged an initial meeting with the family and explained the purpose of the study. Mothers and children were encouraged to ask questions about the research. The researcher explained to children that the study was being carried out with them because their mother had a learning disability.

Sometimes this initial meeting was also attended by another trusted family member or friend who was given the role of asking questions about the project. On a few occasions, the mother requested that the manager of the service (who had made initial contact with them about the research) also be present.

Mothers and children were given the research information leaflets again and the study was explained in detail. Any worries were discussed, such as whether information given to the researcher would be confidential. At the end of the meeting the researcher invited mother and child to take part in the study.

Written consent (for mothers and young people 16-17 years old) and child assent (for children 8-15 years old) to participation in the research was recorded.

A second meeting was then arranged with mothers and children to allow the researcher to assess IQ and adaptive functioning. These two measures took approximately half an hour to complete.

A third meeting took place for the perception of stigma, self-esteem, attachment and social support questionnaires to be completed with the children. These four measures took a total approximate time of thirty-five minutes to complete.

Children were interviewed in their own homes to avoid as much disruption to their daily lives as possible. However, they were given the option of using an NHS facility or being seen at their school if they felt happier doing this. Three children in the study asked to be seen at their school, as they felt better able to concentrate in that environment.

Several of the mothers proved difficult to actually interview. Rather than this indicating reluctance to participate, it was always the case that the mother had forgotten the appointment. Even letters that were sent to back up arrangements made on the telephone did not help, due to reading and writing difficulties.

Sometimes the researcher had to return to a participant's house three or four times before they were able to actually meet.

It was notable that all the children who participated in the research enjoyed doing so. It seemed they found the attention to their personal experiences positive. Many were pleased to be asked to contribute to something that might benefit other children in the future.

Summary

The researcher arranged three separate meetings with the mothers and children to carry out the research procedure over an eighteen month period.

Some mothers were difficult to assess, as they would forget about the organised appointment with the researcher. This may have been reflective of their learning disability and may also have indicated a general level of disorganisation on a day-to-day basis.

Nonetheless, full sets of data were collected on all twenty-four mothers and children.

The next section reports how these results were disseminated to all research participants. The various NHS Trusts and voluntary services that had facilitated the study were also given feedback.

3.10 Dissemination of research findings

The research feedback was given in a written format to both children and mothers.

Children 8-12 years, 13-15 years and 16-17 years were sent a covering letter reminding them of the researcher's visit to interview them and their mother. It also thanked them for their participation in the study and provided contact details for the researcher should they like any further information.

Included with this covering letter was a one-page summary of the research findings. This summary was written in age-appropriate language, in keeping with the research information leaflets that had been sent at the beginning of the study.

Similarly, mothers were sent a covering letter thanking them for their contribution to the study and providing contact details. They were also sent an overview of the research findings, which were designed in conjunction with MENCAP's (2002) guidance on accessible writing and made accessible using Change Picture Bank symbols (www.changepeople.co.uk) to aid understanding.

The feedback sheets to both mothers and children also signposted them to their general practitioner should they wish to seek out services to address any of the issues raised by the study.

All NHS Trusts and voluntary services that facilitated the study were sent a two-page summary of the research findings.

(See appendices Q - T for feedback letters to participants and services)

Summary

All participants and services who contributed to the study were given feedback on the research findings.

The next section turns to the research results and analysis of the data collected in the test measures.

Chapter 4: Results & analysis

4.1 Participant characteristics

A total of twenty-four learning disabled mothers and their children took part in this study.

The mean age of mothers was 40.7 years (SD = 5.8; Range = 28-50 years old).   In total, 87.5% of the participants were married or had a partner with whom they cohabited and 12.5% of the sample was divorced or single.

Mothers were assessed for learning disability using the WASI (Weschler, 1999) and the ABAS-II (Harrison & Oakland, 2000). Mothers' mean score on the WASI was 63.7 (SD = 5.4; Range 55.0 -75.0) and their mean score on the ABAS-II was 59.9 (SD = 6.7; Range = 48.0 – 75.0).

Children's mean age was 11.7 years (SD = 2.8; Range 8.0 – 16.0 years old). Mean age for females (n = 15) was 11.8 years (SD 2.9; Range 8.0 - 16.0 years old). Mean age for males (n = 9) was 10.2 years (SD 1.6; Range 8.0 – 12 years old).

Of the children, 66.7% of the sample had at least one other sibling. 33.3% of the sample were only children or had a sibling they no longer lived with due to removal into care.

Of the children who did have a brother(s) and/or sister(s), the mode number of siblings was 2 (SD.79; Range 1-3). All children were attending mainstream state primary and secondary schools and were assessed to rule out the existence of a learning disability using the WASI and the ABAS-II.

Children's mean score on the WASI was 96.0 (SD = 10.1; Range = 77.0 – 119.0).
Children's mean score on the ABAS-II was 101.1 (SD = 13; Range = 70.0 – 125.0).

None of the children therefore had a learning disability.

Table A below illustrates the means, medians, standard deviations and ranges for mothers' and children's scores on the WASI and the ABAS-II.

Table A: Descriptive statistics for scores on WASI and ABAS-II for mothers and children

	Mother WASI	Mother ABAS-II	Child WASI	Child ABAS-II
Mean	63.7	59.9	96.0	101.1
S.E. Mean	1.1	1.3	2.0	2.6
Median	63.5	60.0	96.5	100.0
Std Deviation	5.4	6.7	10.1	13.0

Figures 2 to 5 below illustrate mothers' and children's respective scores on the WASI and the ABAS-II. Figures 6 to 8 then illustrate the comparison mean between mothers' and children's scores.

Figure 2: Histogram to illustrate children's scores on the WASI

child.wasi

Mean =96.00
Std. Dev. =10.155
N =24

155
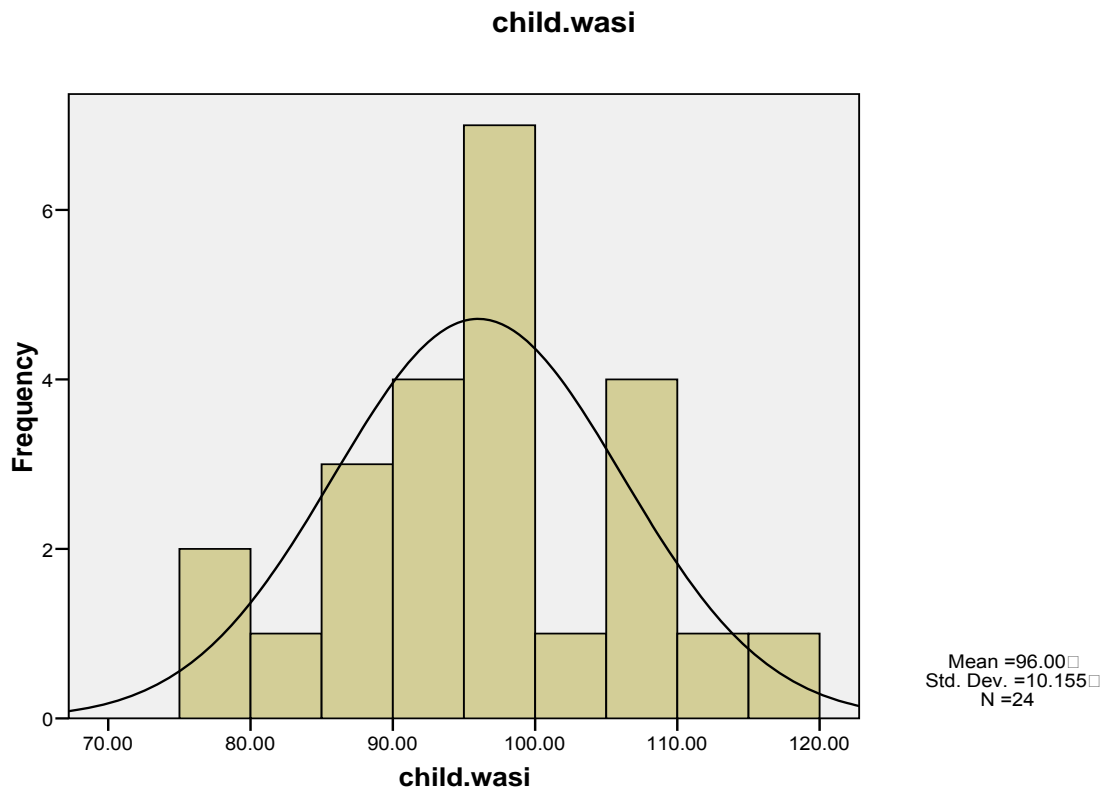
Figure 3: Histogram to illustrate mother's scores on the WASI

mum.wasi

Mean =63.79
Std. Dev. =5.413
N =24

Figure 4: Histogram to illustrate children's scores on the ABAS-II

child.abas

Mean =101.12
Std. Dev. =13.086
N =24

Histogram

Mean =59.96
Std. Dev. =6.76
N =24
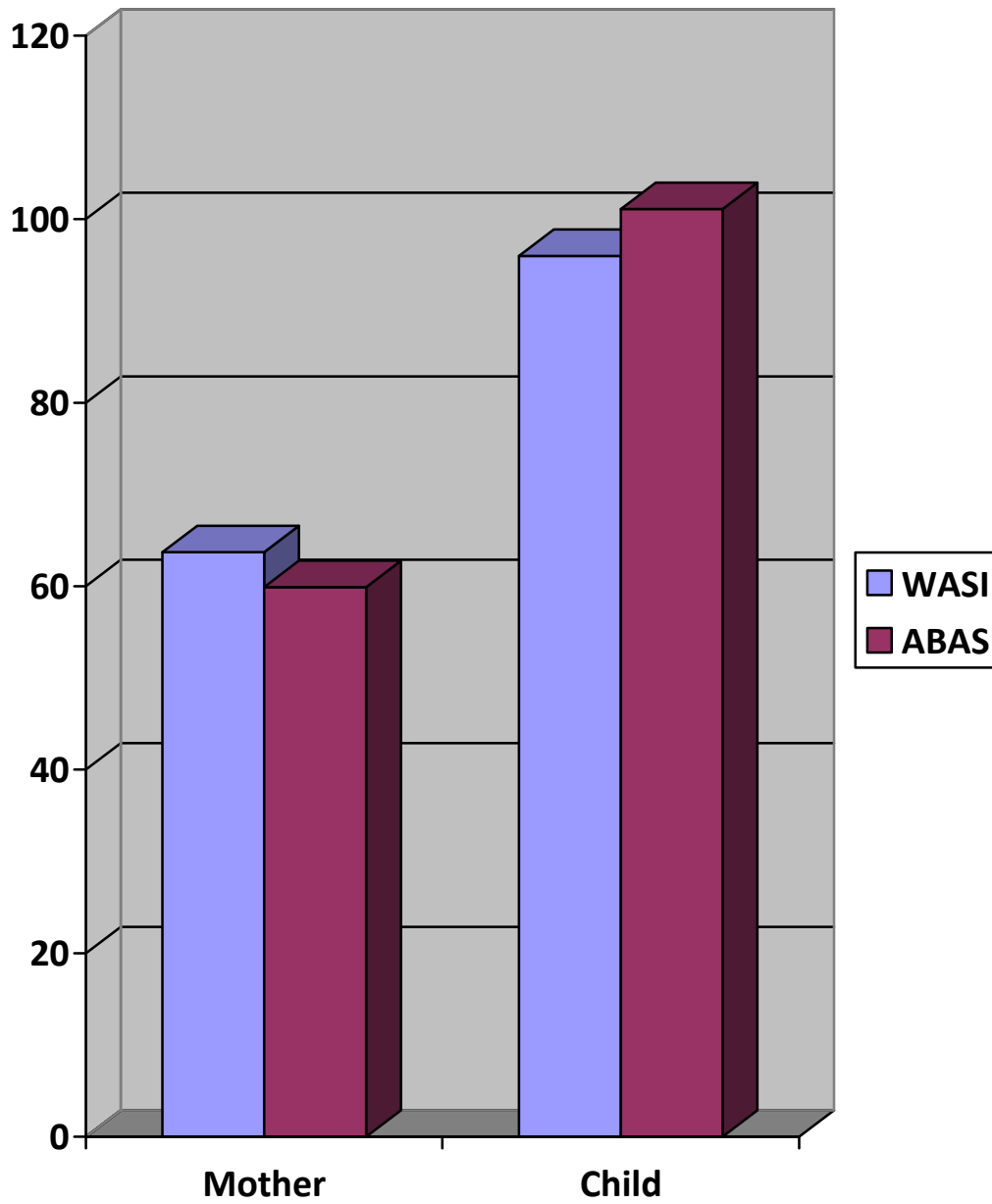
Figure 7: Line chart to illustrate comparison scores between mothers' and children's scores on the WASI
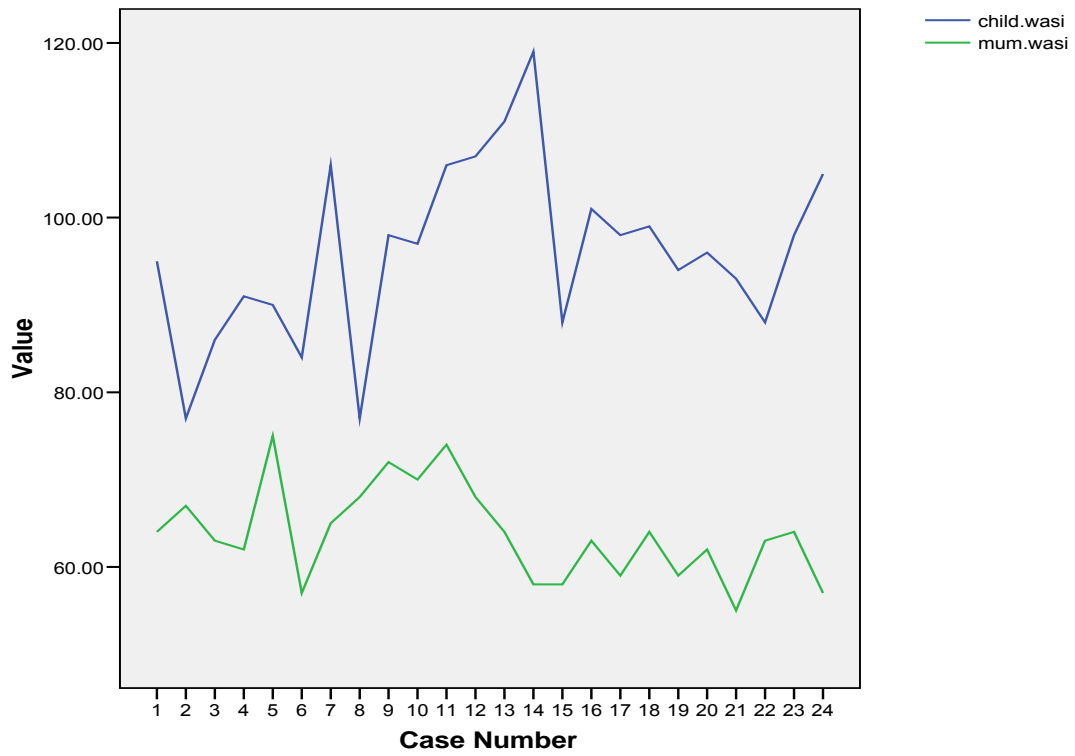
Figure 8: Line chart to illustrate comparison scores between mothers' and children's scores on the ABAS-II
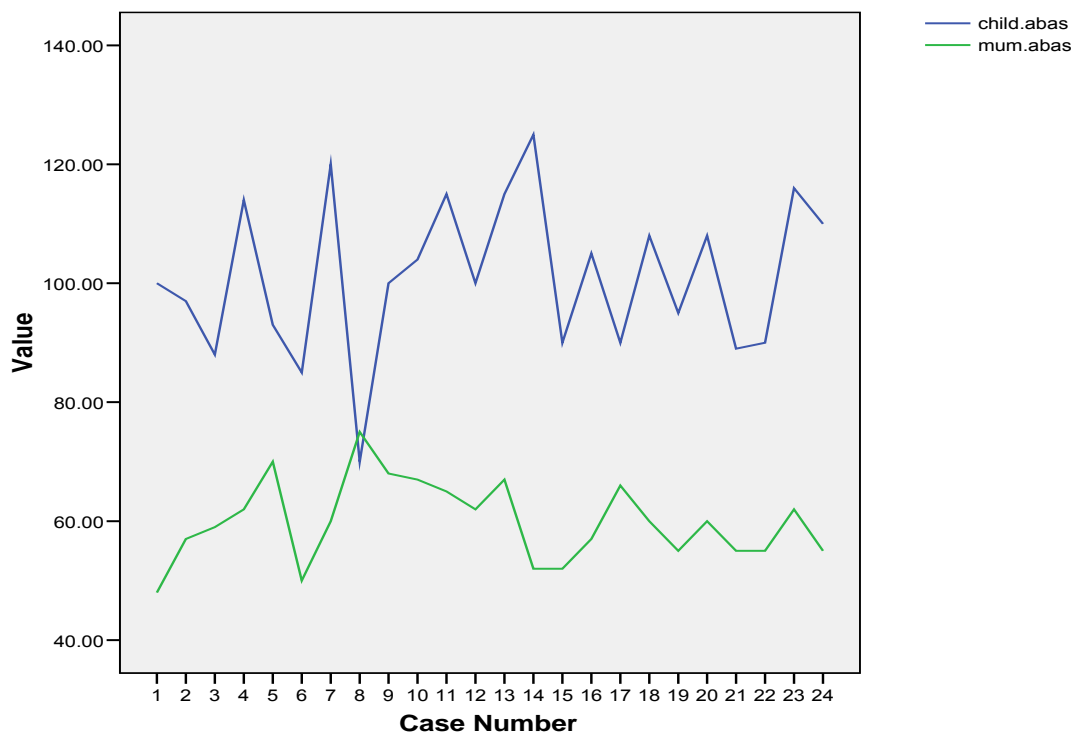
The IQ scores for children in this sample were approximately as expected. The average IQ in the population is 100 and children in this study scored a mean IQ of 96.0. Thus, the IQ of the children in this study fell in the average range. However, looking at the WASI IQ data more closely, the standard deviation was 10.1; hence, there was significant deviation from the mean. Children's scores on the ABAS-II (where the average person would also be expected to score around 100) fell in the average range (mean = 101.1), although they again showed significant deviation from the mean – with a standard deviation of 13.0.

The IQ scores for mothers were also approximately as expected. The mean IQ for mothers was 63.7 and the median 63.4. As with children, a large standard deviation, of 5.4, was seen in the IQ scores. It was an interesting finding that seven of the mothers had IQ scores in the range 55-60. This is noteworthy, as the literature suggests that below IQ 60 is predictive of parenting failure (McGaw and Newman, 2005). Yet all seven of these mothers were still living with their children as their primary care-giver.

Furthermore, mothers' scores on the ABAS-II indicated that their mean level of competence in this regard was low (mean = 59.9). Thus, mothers' adaptive behaviour deficits fell slightly below that which would have been expected on the basis of their IQ score. As adaptive behaviour is a more relevant indicator of parenting ability than IQ (Budd and Greenspan, 1984), this suggests that some mothers may have been struggling to independently provide adequate care for their children.

However, the fact that 87% of these mothers were married or cohabiting possibly explains why their lack of adaptive behaviour skills (and, in seven of the cases, IQ below 60) had not already resulted in their child being removed into care. This suggestion is in keeping with research that has found that the presence of a supportive relationship can protect against parenting failure (Seagull and Scheurer, 1986). Interestingly, the prevalence of married or cohabiting women in this study was slightly higher than in the general population, where it is estimated to be 77% (*Families: Dependent Children – 2004*; Office of National Statistics, 2009).

Of the children included in the study, there were significantly more females than males (62.5% female, 37.5% male). Although the sample size in this research was small, and thus it is difficult to draw firm conclusions, this may suggest that males are more likely to be monitored under child protection plans than females (and as such would have been excluded from this research). However, this issue was not examined within the context of the current study. Nonetheless, there is support in the literature for this suggestion, as studies have shown that males are more prone to externalise distress than girls, leading to higher incidences of conduct disorders (Kim and Cicchetti, 2004), as a result of which they may more easily come to the attention of services. In keeping with this point, Feldman and Walton-Allen (1997) found that behavioural disorders were particularly high amongst males whose mothers had a learning disability. This suggestion is also in line with Achenbach's (1982) wider research on children at-risk, which indicates that boys have an overall 3:1 ratio of disturbances compared to girls. This issue requires further exploration in future research.

Summary

All the mothers included in this research were diagnosed with a learning disability using the WASI and ABAS-II scales.

The majority of the mothers had a partner or were married, which may have been a supportive factor with regards to their parenting role.

None of the children who participated had a learning disability and all were in mainstream school.

The results indicated that children's adaptive behaviour skills were quite high. This was possibly reflective of their role in the family, as children may need to compensate for the day-to-day living tasks their mothers find difficult.

The majority of children who participated in the study were female (62.5%), which may suggest that males were more likely to be involved with child protection agencies

than females (and as such were therefore excluded from participation in this study). Although this is a suggestion that is echoed in the wider literature, this factor was not examined in the context of the current investigation. Consequently, it is a recommendation for future research.

The next section reports the steps that were taken to ensure that the data was normally distributed on the Self-esteem Scale, Perception of Stigma Questionnaire, Adolescent Attachment Questionnaire and the Social Support Questionnaire.

4.2 Normal distribution of variable data

Correlation and multiple regressions require normally distributed data.

Therefore, the data relating to each variable within the path diagram was checked for distribution by assessing skew and kurtosis. This was carried out on data for the Rosenberg Self-esteem Scale, Perception of Stigma Questionnaire, Adolescent Attachment Questionnaire and the Social Support Questionnaire using the Statistical Package for the Social Sciences (SPSS).

SPSS provides a statistical calculation for skew and kurtosis for each variable data as well as a standard error of skew and kurtosis.

If the value of skew and kurtosis for each variable data is less than twice the standard error (ignoring minus sign), then the distribution can be said to be in keeping with that which would be expected in a normally distributed population (Miles and Shevlin, 2007).

Table B and figure 9 below report the observed skew, kurtosis and standard error for each questionnaire, illustrating normal distribution of data.

Table B: Variability measures for each variable illustrating normal distribution of data

	Self-esteem	**Stigma**	**Attachment**	**Social support**
Skewness	-.442	.812	-.362	-.550
Std. error of Skewness	.472	.472	.472	.472
Kurtosis	.619	.093	.775	-.026
Std. error of kurtosis	.918	.918	.918	.918

self.esteem

Mean =28.17
Std. Dev. =6.989
N =24

stigma

Mean =3.62
Std. Dev. =2.70
N =24

AAQ.Full.Score

Mean =15.83
Std. Dev. =4.743
N =24

ssq6s

Mean =5.25
Std. Dev. =0.944
N =24
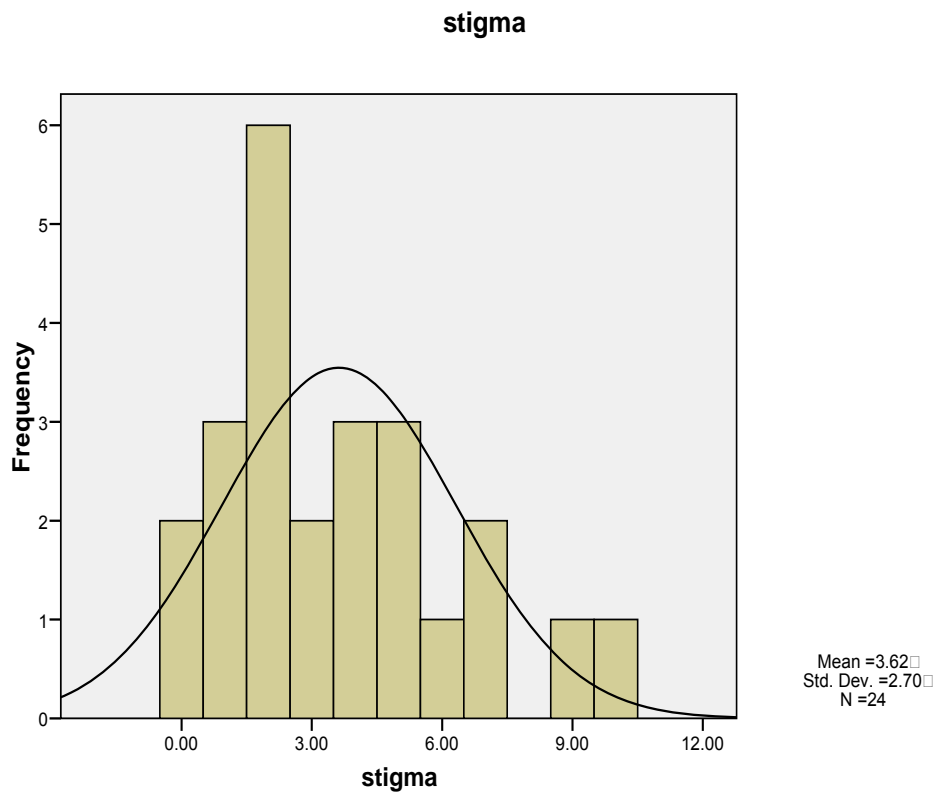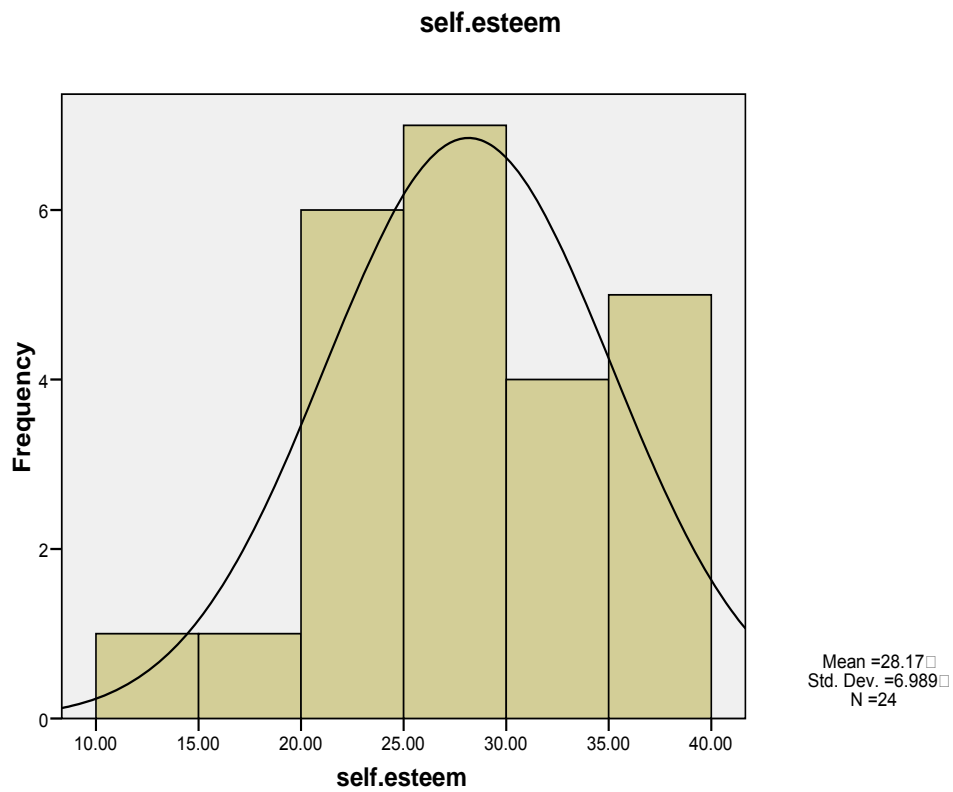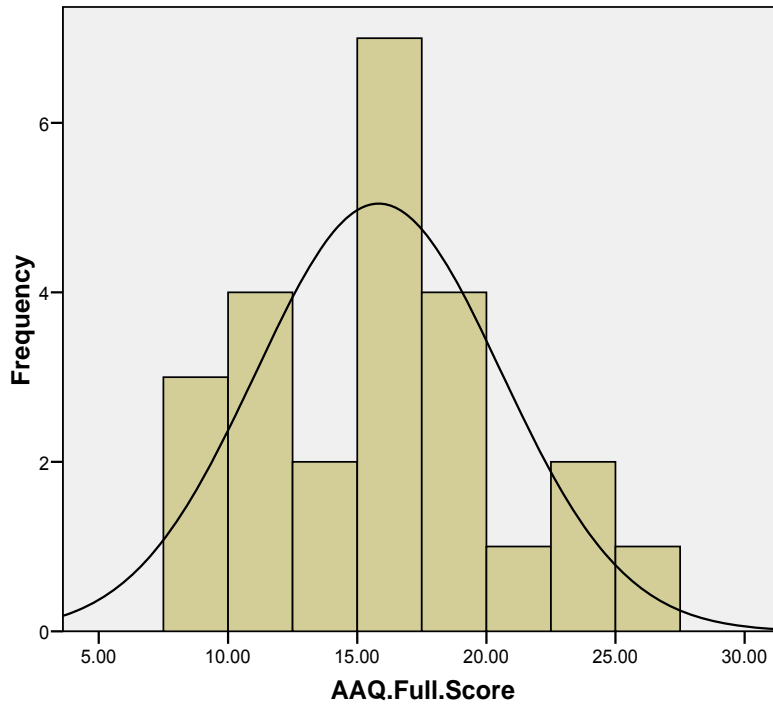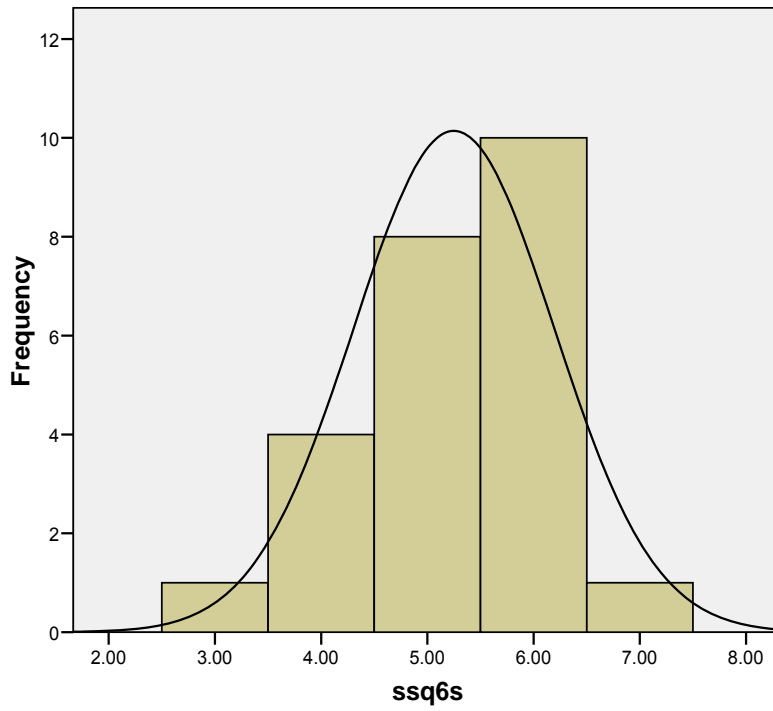
Summary

A statistical calculation was performed to check for normal distribution of data on the Self-esteem Scale, Perception of Stigma Questionnaire, Adolescent Attachment Questionnaire and Social Support Questionnaire.

Once this had been established, correlations and regressions could then be carried out.

The next section reports children's scores on the above four measures and provides initial analysis to explain these findings.

4.3 Children's collective scores on measures for self-esteem, perception of stigma, attachment and social support

The data below looks at males' and females' collective scores on the Rosenberg Self-esteem Scale, the Perception of Stigma Questionnaire, Adolescent Attachment Questionnaire and the Social Support Questionnaire.

In reading this data, it is important to note that higher scores on the attachment and perception of stigma measures are indicative of *maladaptive* functioning.

However, higher scores on the self-esteem and social support measures reflect *adaptive* functioning.

Table C gives the descriptive data for females' and males' collective scores across the test measures. Figures 10 to 17 give cumulative frequency charts and distribution histograms to show children's scores across all 4 measures.

Table C: Descriptive statistics for males' and females' collective scores on test measures

Measure	Number of participants	Range of scores on measure	Mean	Standard Deviation
Rosenberg Self-esteem measure	24	10-40	28.1	6.9
Perception of Stigma Questionnaire	24	0-10	3.6	2.6
Adolescent Attachment Questionnaire	24	9-27	15.3	5.7
Social Support Questionnaire	24	3-7	5.2	.94

Self-esteem

The average score on the Rosenberg Self-esteem Scale is 25, a score above which indicates good self-esteem. The children in this study showed a mean = 28.1 (range = 10-40) on this measure.

In total, 33.3% of this sample reported low levels of self-esteem. Figure 10 below illustrates the cumulative frequency of children's scores on this scale.

Figure 10: Cumulative frequency chart to show children's scores on the Rosenberg Self-esteem Scale
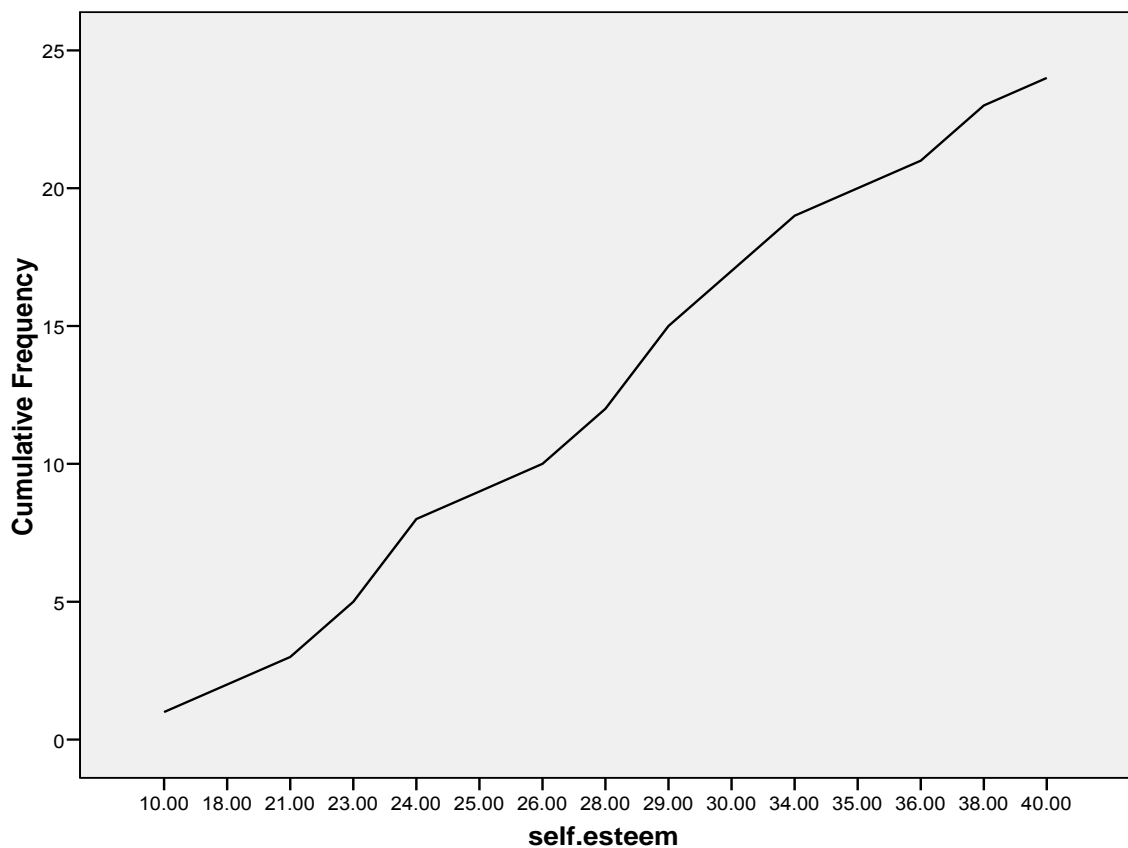
Looking at the distribution of data more closely, while the majority of scores fall towards the higher range, a number of low scores reported. Figure 11 below illustrates the distribution of scores.

self.esteem

Mean =28.17
Std. Dev. =6.989
N =24
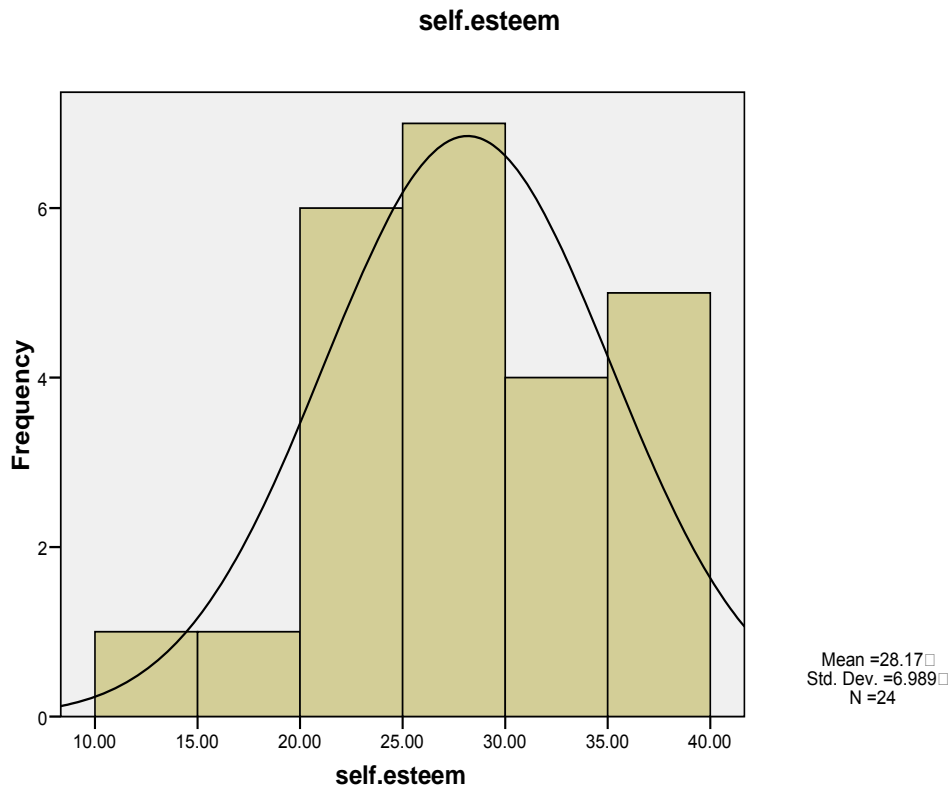
It is possible to compare the children's mean scores in this sample with Perkins *et al.* (2002) study, the only other published paper that has used this measure with the children of parents with learning disabilities.

The children in Perkins *et al.* (2002) study demonstrated a mean = 20 (range = 10 - 40) on the Rosenberg Self-esteem Scale, where children in this cohort scored a slightly higher mean = 28.1.

Child perception of stigma

The mid-point score on this scale was 6, scores above which indicated higher levels of perceived stigma. Children's mean score on this measure was 3.6 (range = 0-10). The majority of the sample reported a low awareness of perceived stigma in relation to their mother. Figure 12 below illustrates the cumulative frequency of children's scores on this scale.

__Figure 12: Cumulative frequency chart to show children's scores on the Perception of Stigma Questionnaire__
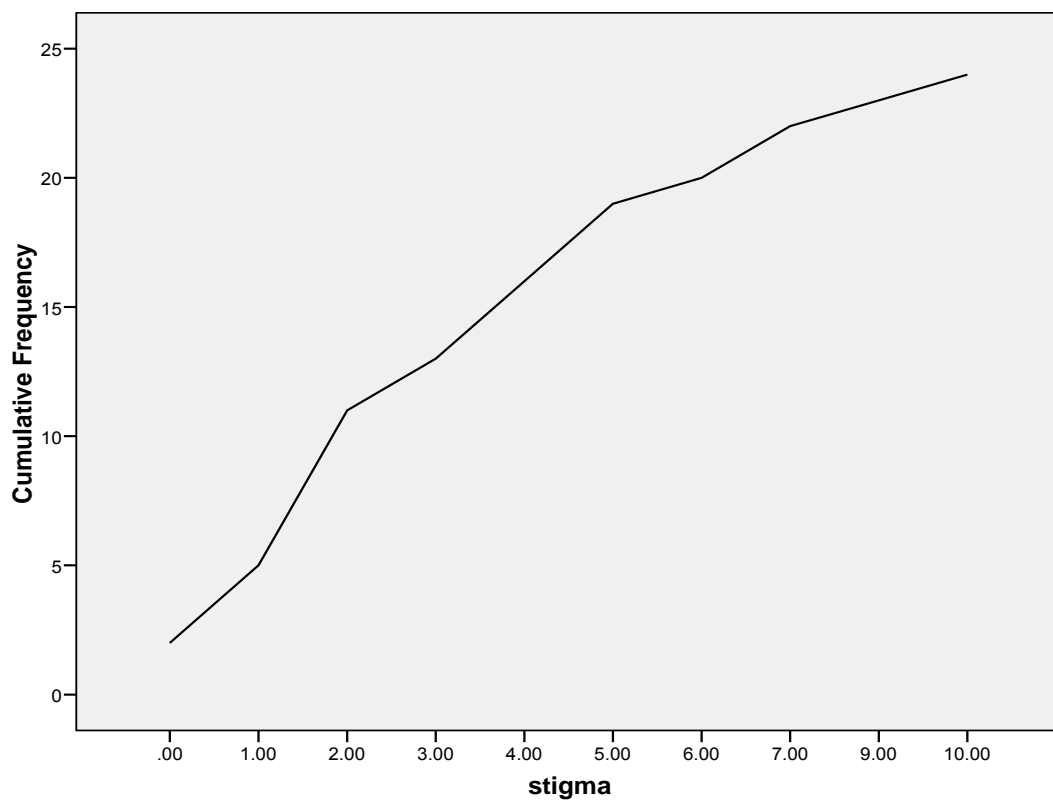
However, 16.7% of the sample reported a high level of perceived stigma. Figure 13 below demonstrates these higher scores, including outlier scores.

stigma

Mean =3.62
Std. Dev. =2.70
N =24
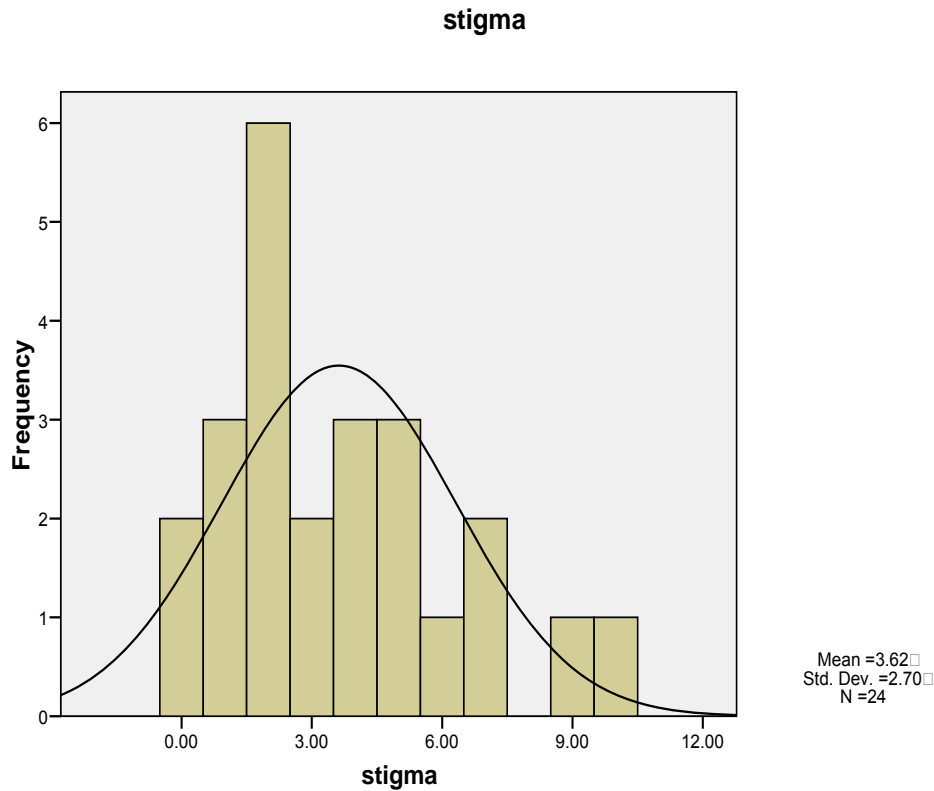
stigma

These findings can be compared with Perkins *et al.*'s (2002) study, where children reported a mean = 5 on the scale (range 0-12). Overall, children in the current research scored lower levels of perceived stigma in relation to their mother than the Perkins *et al.* (2002) sample.

A child's perception of stigma in relation to their mother did not appear to be influenced by age, with younger children reporting similar rates as older children. This finding was not in keeping with research carried out by Szalacha *et al.* (2007), who found that vulnerability to perceived discrimination increased with age.

The risk to children who perceive courtesy stigma is that they internalise that negativity, leading to self-stigma (Corrigan *et al.*, 2006). Where this occurs, a risk is posed to a child's self-esteem (Corrigan *et al.*, 2006; Perkins *et al.*, 2002; Wahl and

Harman, 1989). In fact, Szalacha *et al*. (2007) suggest that, even where a child worries about the potential for discrimination to occur, this may negatively impact upon self-worth.

Consequently, 16.7% of this sample reported a level of perceived stigma that was likely to pose a risk to their self-esteem.

Attachment

On the Adolescent Attachment Questionnaire, scores above 18 indicate significant attachment-related difficulties. Children's results in this study showed a mean = 15.3 (range = 9-27).

In total, 20.8% of the sample reported a score above 18. Hence, some children reported high levels of difficulty in their attachment relationship with their mother.

Figure 14 below indicates children's cumulative scores on this measure.

Figure 14: Cumulative frequency chart to show children's scores on the Adolescent Attachment Questionnaire
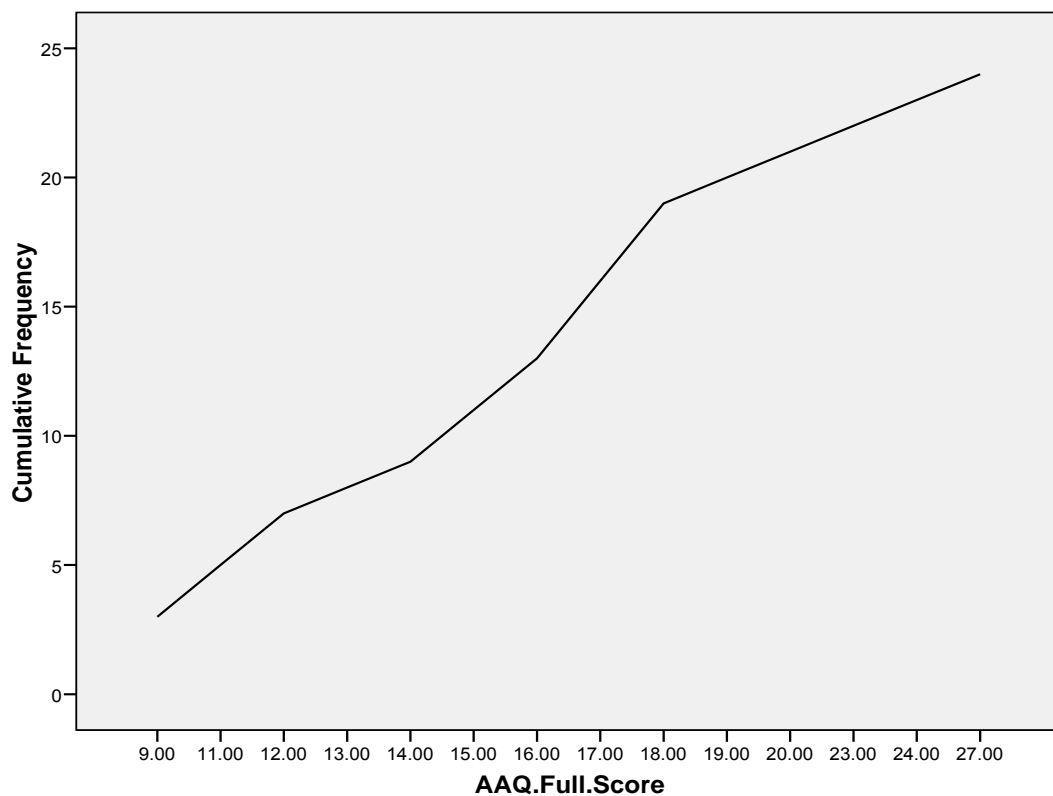
Figure 15 below illustrates the distribution of children's overall scores on the Adolescent Attachment Questionnaire.

AAQ.Full.Score
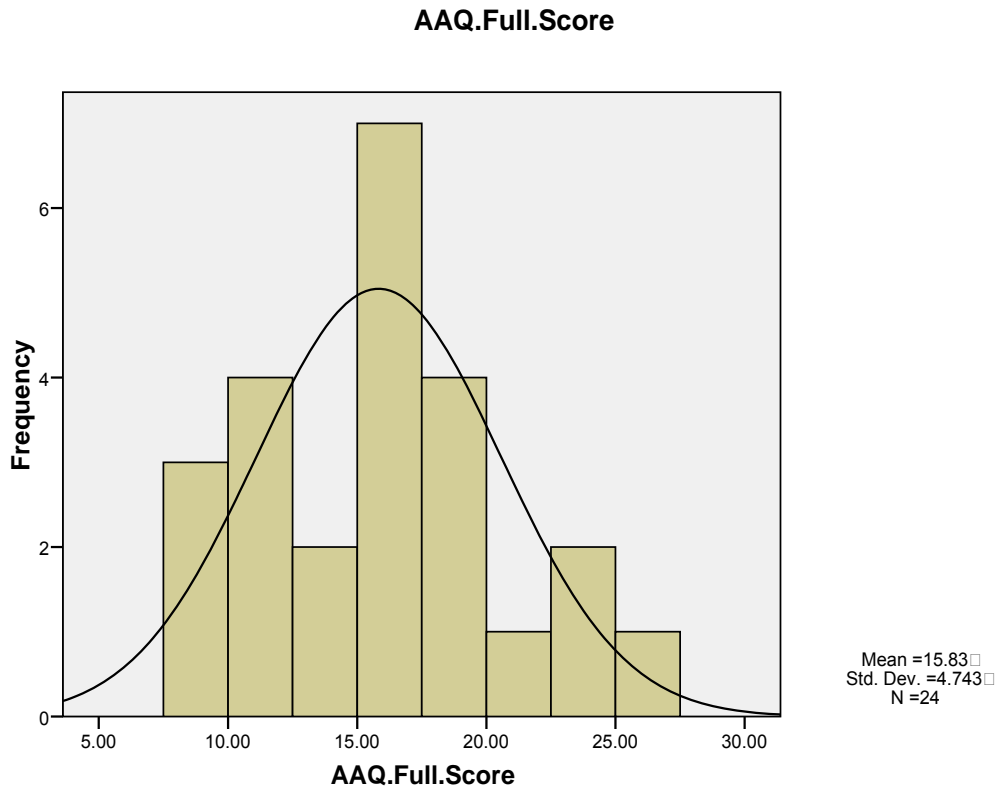
Approximately one-fifth of the sample therefore indicated insecure attachment to their mother. Interestingly, this figure is lower than the established distribution pattern of attachment style in normal populations, where generally one-third is insecure and two-thirds secure (van IJzendoorn *et al*., 1999).

One explanation for this finding is that the sample in the current research was heavily biased. Mothers recruited to the study were all known to services. Therefore, given the scrutiny these particular mothers were parenting under, they were likely to be operating at the robust end of the attachment continuum.

Social support

The average score on the Social Support Questionnaire is 5, a score above which indicates good levels of social support. The children in this study scored mean = 5.2 (range = 3-7).

Just under half (45.6%) of the sample reported unsatisfactory levels of social support.

Figures 16 and 17 below illustrate children's scores on this measure.

Figure 16: Cumulative frequency chart to show children's scores on the Social Support Questionnaire
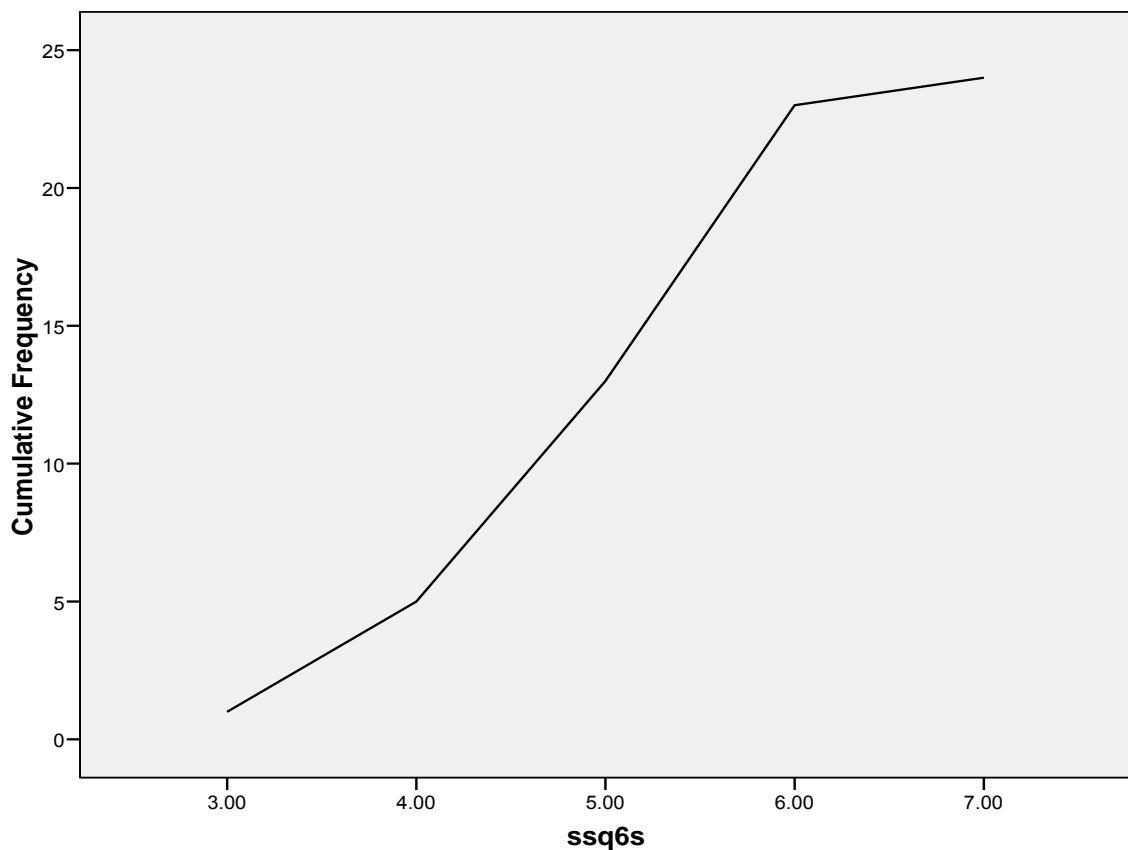
Figure 17: Histogram to illustrate children's scores on the Social Support Questionnaire

ssq6s

Mean =5.25
Std. Dev. =0.944
N =24
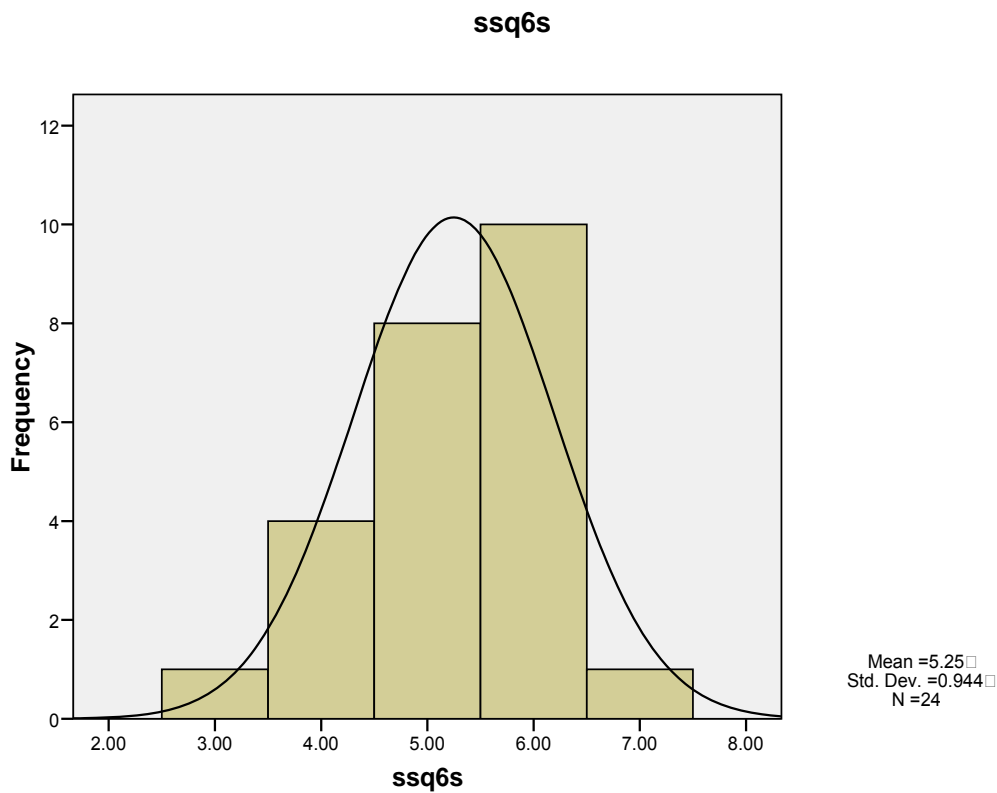
Interestingly, most children listed family members as supports rather than friends. No significant differences were seen between the younger and older children's listed relationships. In total, 72.3% of children reported their father, or their mothers' boyfriend as a key support. Collectively, the children in this study appeared to have few peer relationships.

It was surprising that this was the case with the older children, as research by Allen *et al.* (1998) has suggested that peer relationships normally take over from family relationships during adolescence.

Peer relationships can be vital for children facing hardship. Research has shown that, where it can be achieved, such friendships act as powerful resilience factor for children facing adversity (Bolger and Patterson, 2001a; Bolger *et al.,* 1988; Schwartz *et al.,* 2000). Thus, the children in this study did not appear to be benefitting from the protective effects of supportive peer relationships.

Many children named pets as key emotional supports, despite the researcher initially challenging this. It appeared that many children did genuinely perceive their dog, cat or hamster to be able to empathise with them and care about them if they were stressed or worried.

Some evidence for pets as sources of support is seen in the literature. Hart, Blincow and Thomas (2007) point out that those children with neglectful and/or abusive experiences are often able to emotionally attach to a pet far more easily than they do to adults or peers. Similarly, Mallon (1992) reports that the very process of simply being able to care about a pet can have a therapeutic advantage for some children.

Summary

These results found that 33.3% of children reported low levels of self-esteem. In total, 16.7% of the sample reported a high level of perceived stigma in relation to their mother and 20.8% reported attachment-related problems. Just under half (45.6%) of the children reported unsatisfactory levels of social support.

Having looked at children's overall scores on the four test measures, the next section then breaks this data down to analyse the comparison between males' and females' scores. This analysis yields some interesting differences.

4.4 Comparison of females' and males' scores on self-esteem, perception of stigma, attachment and social support measures

The data below provides descriptive comparison for females and males scores on the four test measures – Rosenberg Self-esteem Scale, the Perception of Stigma Questionnaire, Adolescent Attachment Questionnaire and the Social Support Questionnaire.

Males' and females' comparison scores are also considered on the subscales of the Adolescent Attachment Questionnaire: Angry Distress, Availability and Goal Corrected Partnership scales.

Again, in reading this data, it is important to note that higher scores on the attachment and stigma measures indicate *maladaptive* functioning. Higher scores on the self-esteem and social support measures indicate *adaptive* functioning.

Tables D and E and figures 18 – 31 below show the comparison between females' and males' scores on the self-esteem, perception of stigma, attachment and social support measures.

Table D: Descriptive statistics for males' and females' scores on test measures

Measure	Number of participants	Range of scores on measure	Mean	Standard Deviation
Rosenberg Self-esteem Scale (females)	15	10-38	25.8	7.0
Rosenberg Self-esteem Scale (males)	9	24-40	32.0	5.2
Perception of Stigma Questionnaire (females)	15	1-10	3.8	2.9
Perception of Stigma Questionnaire (males)	9	0-7	3.2	2.2
Adolescent Attachment Questionnaire (females)	15	11-27	17.1	4.8
Adolescent Attachment Questionnaire (males)	9	3-18	12.3	6.0
Social Support Questionnaire (females)	15	3-6	4.9	0.8
Social Support Questionnaire (males)	9	4-40	9.5	11.4
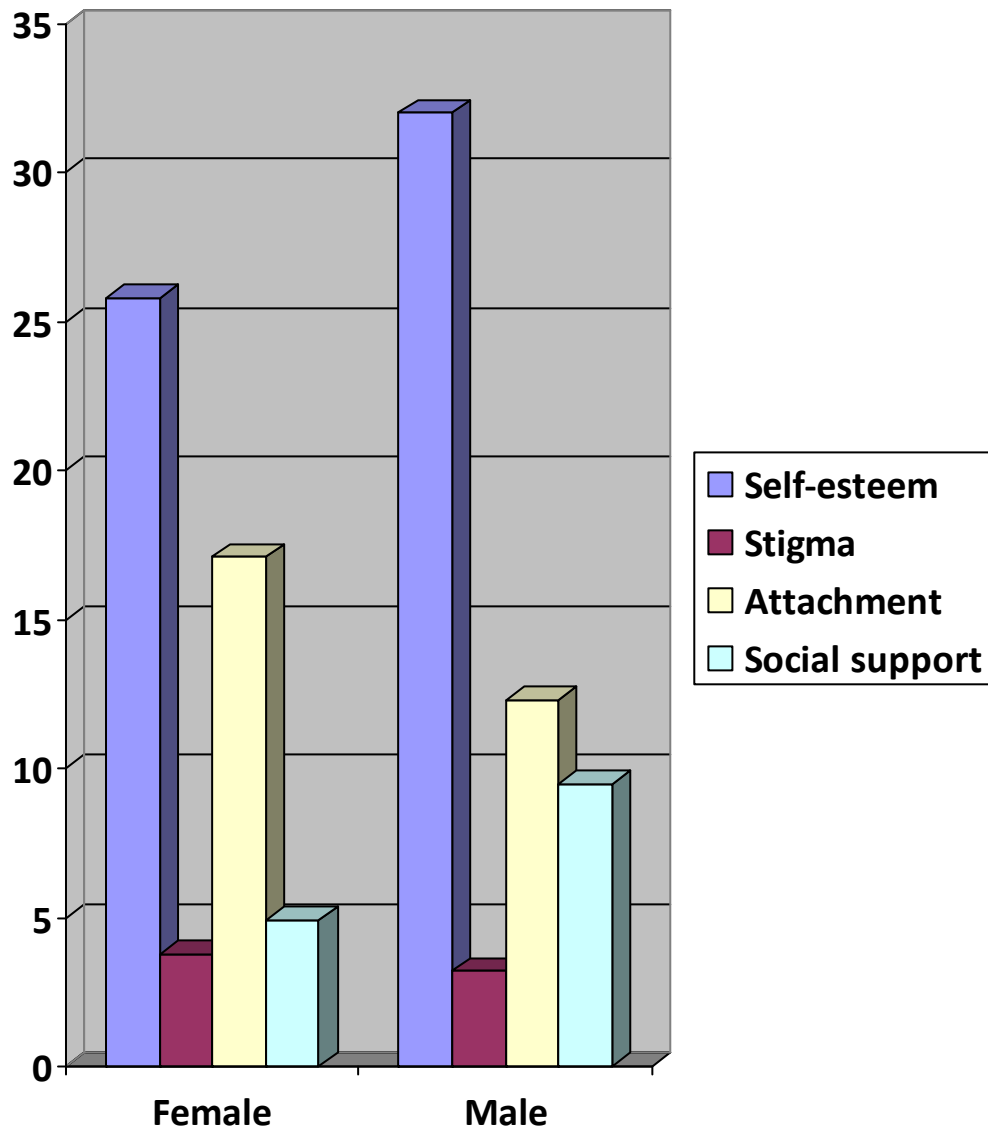
It is interesting to note that males reported higher levels of self-esteem and social support and lower levels of perceived stigma and attachment problems than females. These findings are discussed in more depth below.

Self-esteem

Significant differences were seen on the Rosenberg Self-esteem Scale. 46.7% of the female sample reported below average self-esteem, where only 11.1% of the male sample reported low self-esteem. Figures 19 - 21 below illustrate the difference between females' and males' scores.

__Figure 19: Line chart to illustrate females' and males' scores on the Rosenberg Self-esteem Scale__

Histogram

female.selfesteem

Mean =25.87
Std. Dev. =7.019
N =15

Histogram

Mean =32.00
Std. Dev. =5.268
N =9

One explanation for the differences observed may be that all of the adolescents in this sample were female (range 8.0 – 12 years old for males and range 8.0 - 16.0 years old for females.) This finding is in keeping with previous research, which has found that females demonstrate lower levels of self-esteem than males during adolescence (Kling *et al.*, 1999).

Perception of stigma

It was notable that males in the cohort reported low levels of perceived stigma with respect to their mother (the highest male score on the measure was 4, where scores above 6 represent higher levels of perceived stigma). Yet, 26.7% of the females scored 6 or above on the scale. Figures 22-24 illustrate the differences between males and females scores.

Figure 22: Line chart to illustrate females' and males' scores on the Perception of Stigma Questionnaire

Histogram

Mean =4.80
Std. Dev. =2.624
N =15
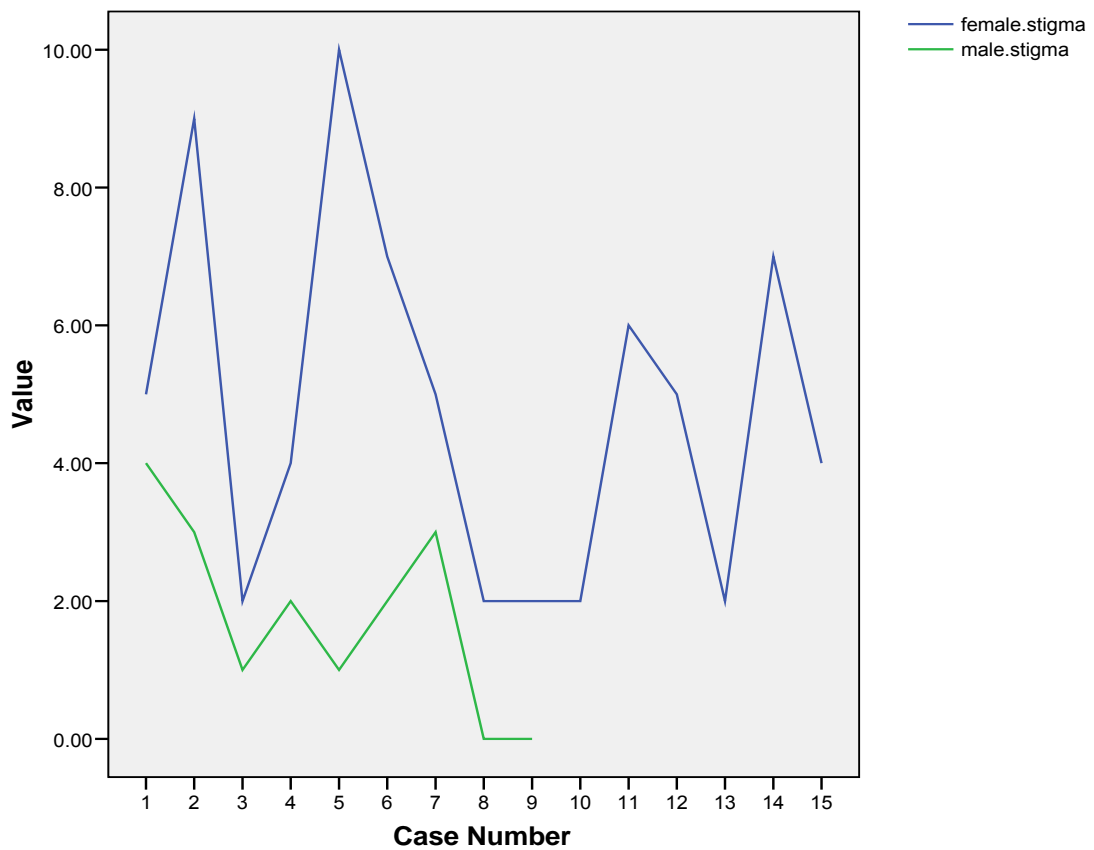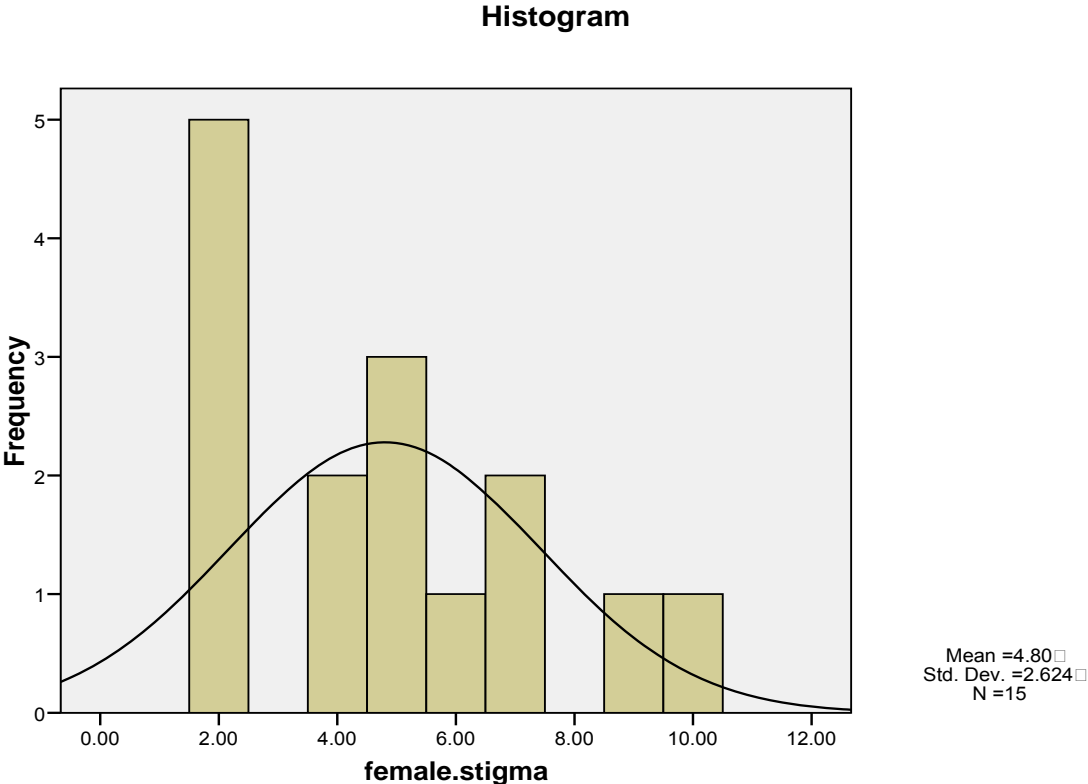
Figure 24: Histogram to illustrate males' scores on the Perception of Stigma
Questionnaire

Histogram

Mean =1.78
Std. Dev. =1.394
N =9
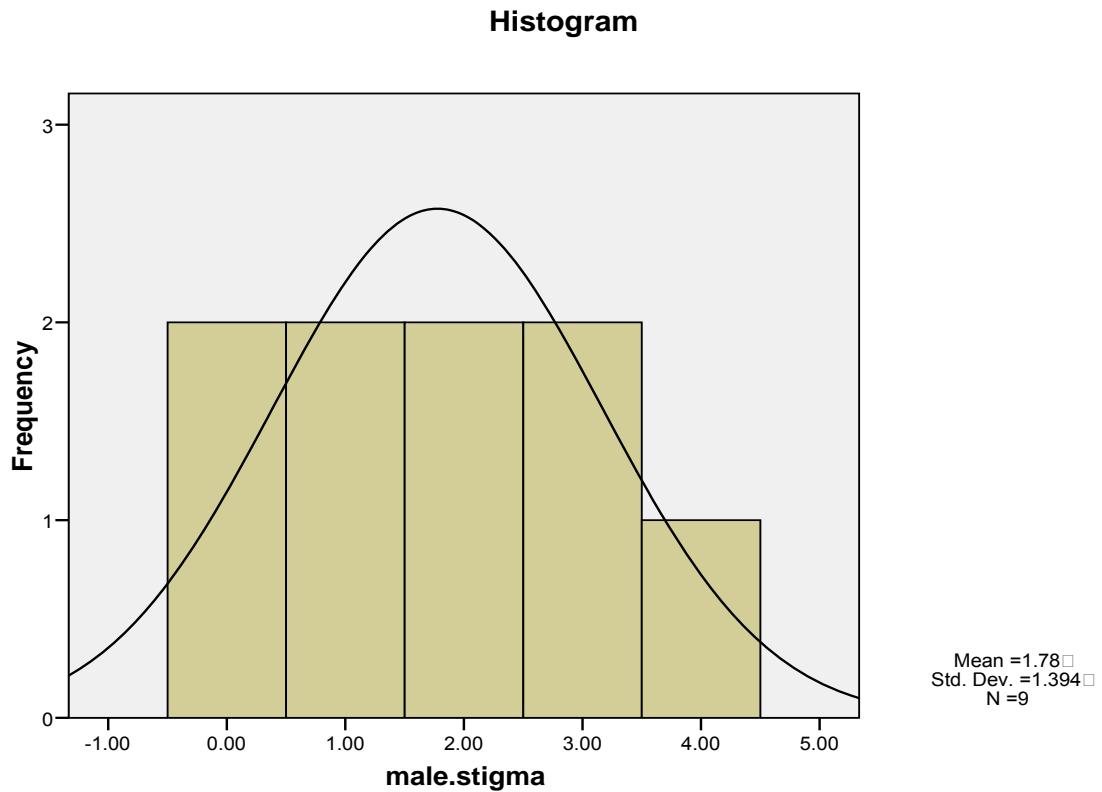
Females' higher reported levels of perceived stigma could not be explained by child age. Although females in this research were older than males, no significant differences were seen between other older and younger female scores on perceived stigma. This finding was not in keeping with previous research by Szalacha *et al.* (2007), which suggested that vulnerability to perception of stigma increases with child age. Perhaps females' elevated scores on this measure may be explained by their increased rates of attachment difficulties, which are discussed further below.

Attachment

Table E below illustrates females' and males' scores on each of the three subtests of the Adolescent Attachment Questionnaire – Angry Distress, Availability and Goal Corrected Partnership. On these individual subtests, scores above 6 indicated attachment-related difficulties.

Table E: Descriptive statistics for males' and females' scores on the Adolescent Attachment Questionnaire subtests

AAQ subscales	Number of participants	Range of scores on measure	Mean	Standard Deviation
Angry distress (females)	15	3.0-11.0	6.6	2.5
Angry distress (males)	9	3.0-9.0	4.8	2.7
Availability (females)	15	3.0-12.0	5.1	2.3
Availability (males)	9	3.0-6.0	3.7	2.0
Goal corrected partnership (females)	15	3.0-10.0	4.9	2.0
Goal corrected partnership (males)	9	3.0-6.0	3.6	1.7

The differences in females' and males' scores are illustrated in figure 25 below.

__Figure 25: Histogram to show comparison means for children's scores on Adolescent Attachment Questionnaire subtests__
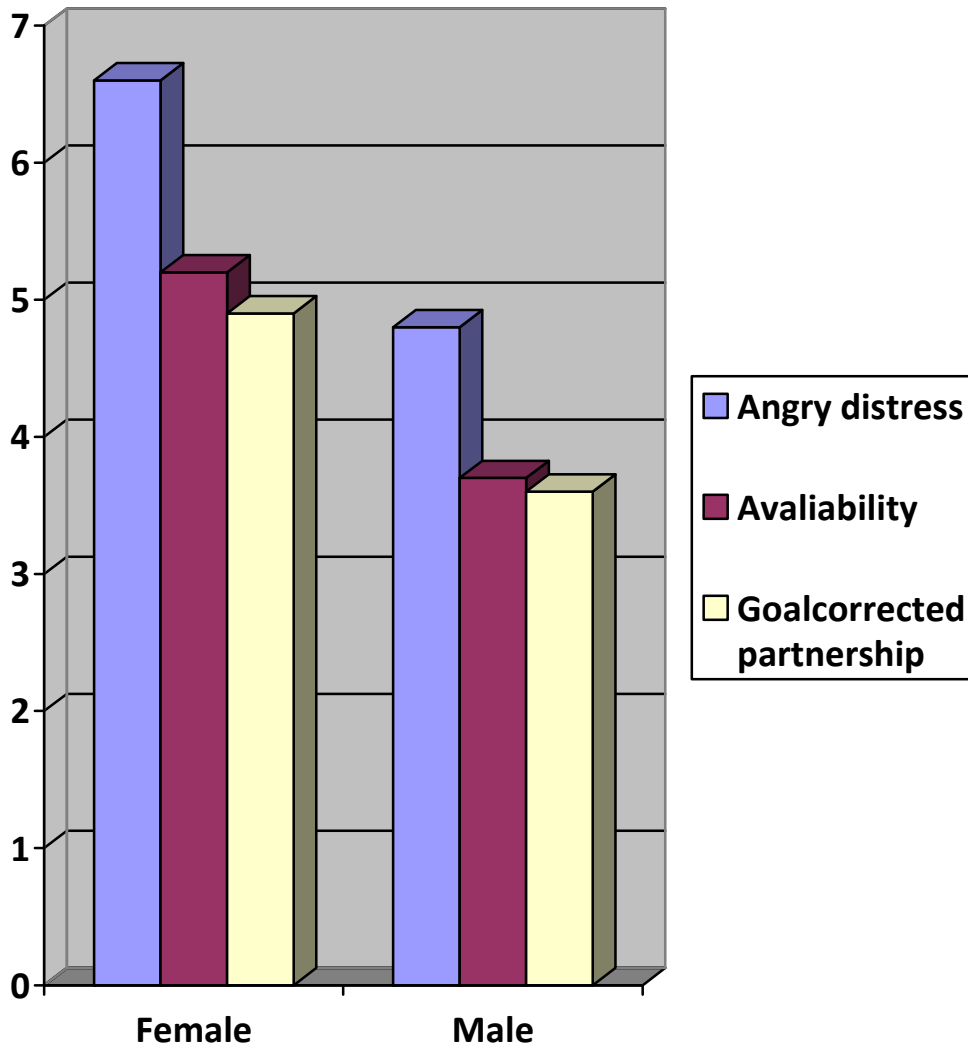
Attachment Subscales:

Angry Distress Subscale

The Adolescent Attachment Questionnaire's Angry Distress scale taps negative responses to the perceived unavailability of the attachment figure. As Bowlby (1973) observed, the anxiety caused by feeling that an attachment figure may be inaccessible or unresponsive generates hostility.

Both females (46.7%) and males (44.4%) reported the highest level of attachment problems on the Angry Distress scale, which taped negative affective responses to the perceived unavailability of their mother. These scores are illustrated in figure 26 below.

Figure 26: Line chart to illustrate females' and males' scores on the Angry Distress subscale of the Adolescent Attachment Questionnaire
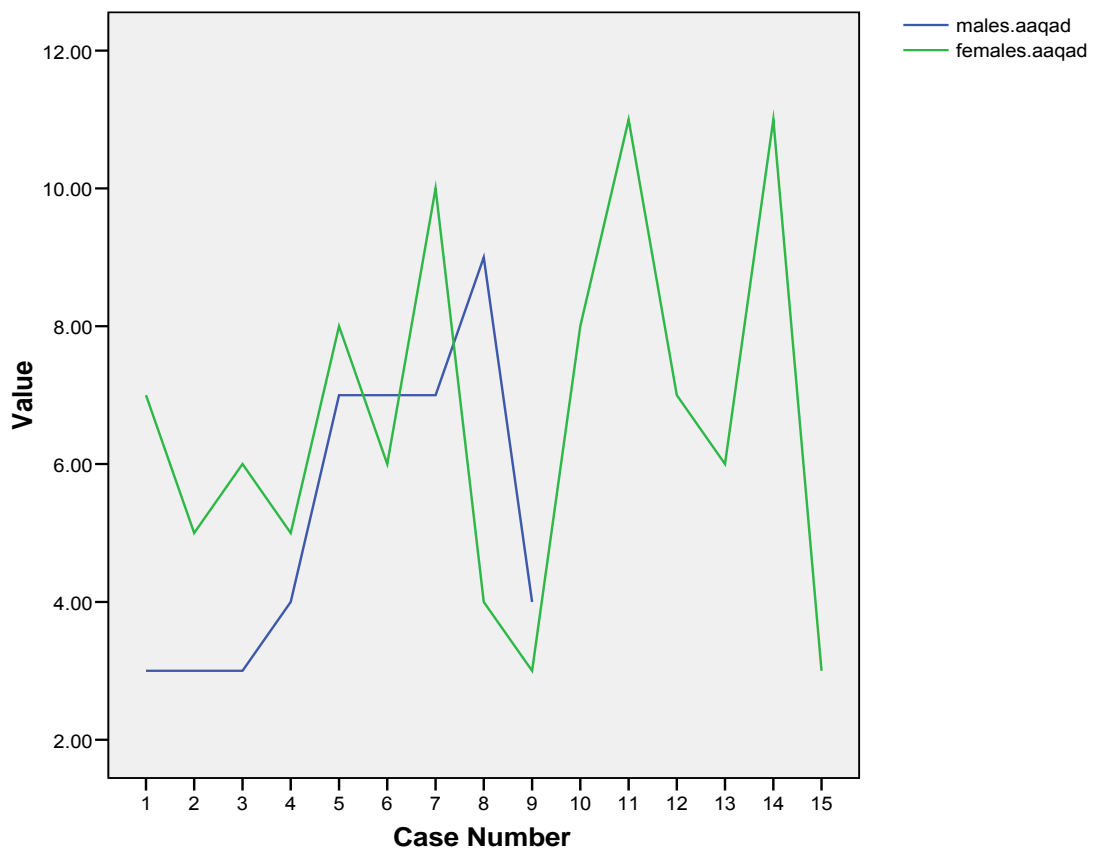
Figure 27 illustrates females' scores on the Angry Distress subscale. This histogram shows some high outlier scores, demonstrating that 46.7% of females reported particularly strong feelings of hostility towards their mother as a result of their parents' perceived emotional unavailability.

Figure 27: Histogram to show females' scores on the Angry Distress subscale of the Adolescent Attachment Questionnaire

Histogram

Mean =6.67
Std. Dev. =2.582
N =15
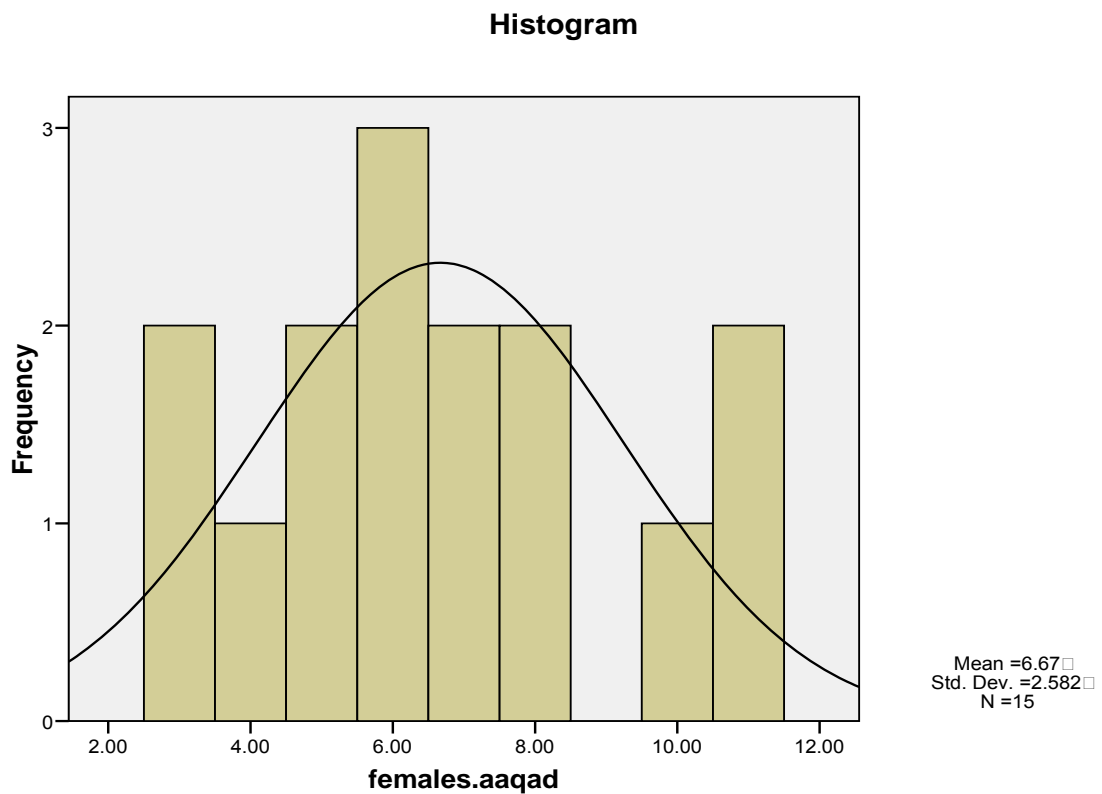
Figure 28 below illustrates males' scores on the Angry Distress subscale. This histogram shows a lower cluster of scores reporting little attachment difficulty, while the higher cluster of scores indicates significant Angry Distress. Thus, 44.4% of males reported particularly strong feelings of hostility towards their mother as a result of their parents' perceived emotional unavailability.

Histogram
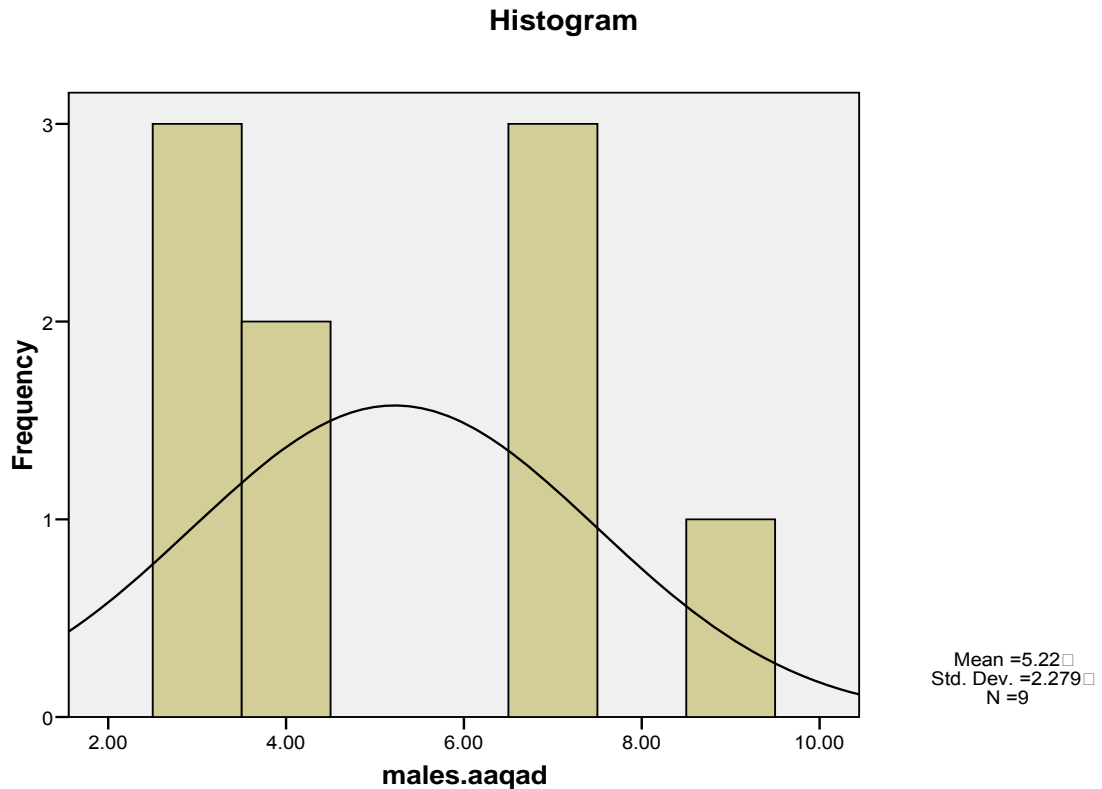
The Angry Distress subscale on the Adolescent Attachment Questionnaire has been found to have strong convergent validity with preoccupied attachment style on Main's (1985) Adult Attachment Interview (West *et al.,* 1998), the gold standard in adult and adolescent attachment measures (Cassidy and Shaver, 1999). It is interesting to note that this attachment category has been found to strongly associate with Axis II psychopathology in DSM-IV (Hesse, 1999).

Therefore, these findings perhaps elucidate one of the pathways by which children of parents with learning disabilities are at greater risk of mental health problems than the general population (McGaw *et al.*, 2007).

Availability subscale

The Adolescent Attachment Questionnaire Availability subscale assesses the extent to which the adolescent has confidence in the attachment figure as reliably accessible and responsive to most of his/her attachment needs (West *et al.,* 1998).

Interestingly, where 13.3% of the female sample indicated difficulties with emotional availability in their attachment relationship, males did not score above the threshold on this subscale. Figure 29-31 below illustrate females' and males' scores.

Figure 29: Line chart to illustrate females' and males' scores on the Availability subscale of the Adolescent Attachment Questionnaire

Histogram

Mean =5.13
Std. Dev. =2.386
N =15

Histogram
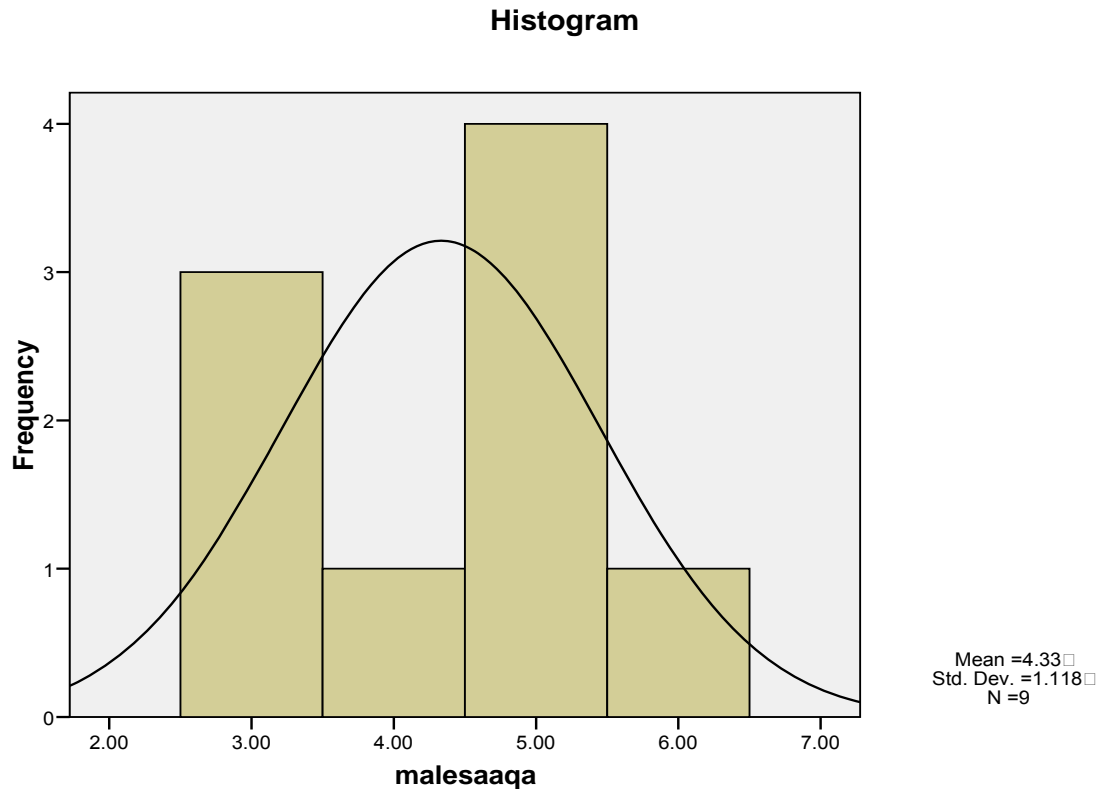
These results suggest a number of females in the sample were insecure about the extent to which their mother would be available to them during times of distress and anxiety. This was not the case for the males.

One explanation for this may be that the females in this sample were older (range 8.0 - 16.0 years old) than the males (range 8.0 – 12 years old). Quite possibly, as children get older, parents are required to take less responsibility for their child's safety. This may result in a sense of parents being less physically available to their children during adolescence. In the absence of a peer group to turn to, this may leave the older children more isolated.

It may also be that, as females reach puberty, they seek increased support from their mother to help guide them through issues such as menstruation. If this support is

unavailable, it generates disruption in the attachment relationship.   As Steinberg (1990) pointed out, the mother-daughter relationship can become especially strained during adolescence. Hence, this may be one explanation for female's scores on the Availability scale.

Goal Corrected Partnership subscale

The Adolescent Attachment Questionnaire includes a Goal Corrected Partnership subscale to assess the extent to which the child considers and has empathy for their primary attachment figure.

As with the Availability subscales, 13.3% of females indicated frustration with this aspect of their attachment relationship. Yet males did not meet the threshold, indicating few difficulties in this regard. Figure 32 to 34 below illustrates males' and females' scores on this subtest.

Figure 32: Line chart to illustrate females' and males' scores on the Goal Corrected Partnership subscale of the Adolescent Attachment Questionnaire
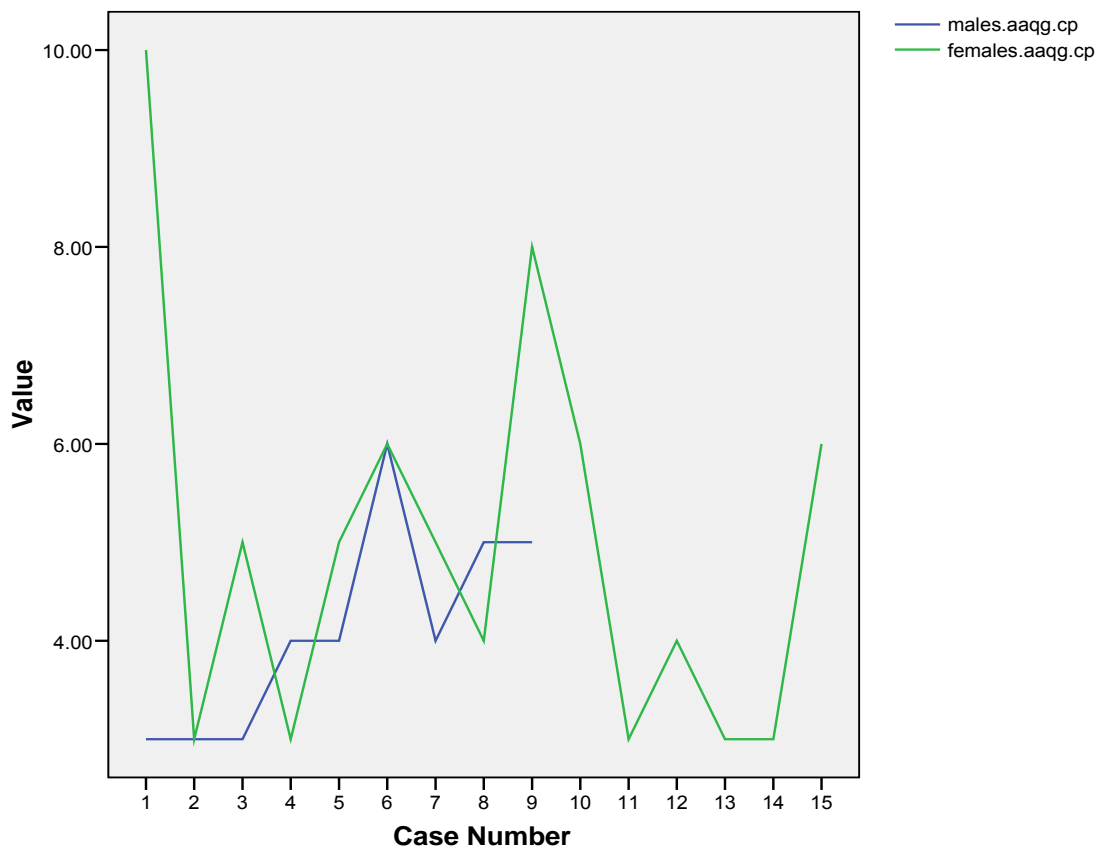
Figure 33: Histogram to show females' scores on the Goal Corrected Partnership subscale of the Adolescent Attachment Questionnaire

Histogram

females.aaqg.cp

Mean =4.93
Std. Dev. =2.052
N =15

Histogram

males.aaqg.cp

Mean =4.11
Std. Dev. =1.054
N =9
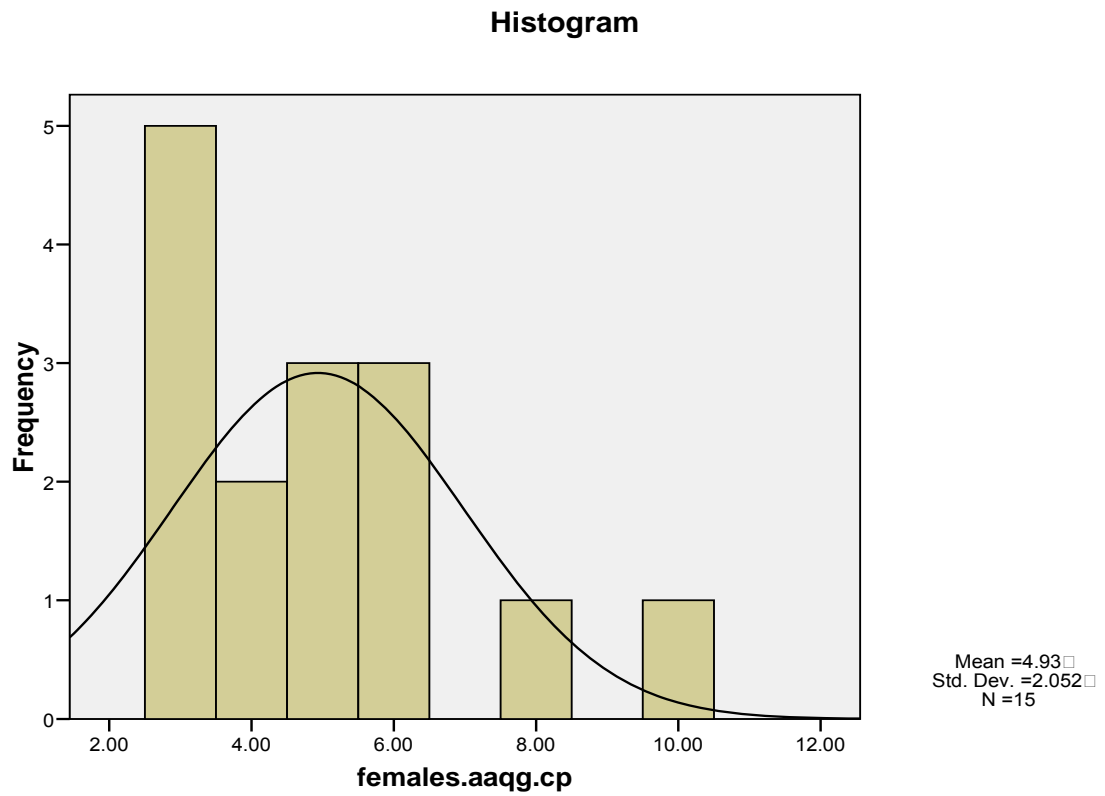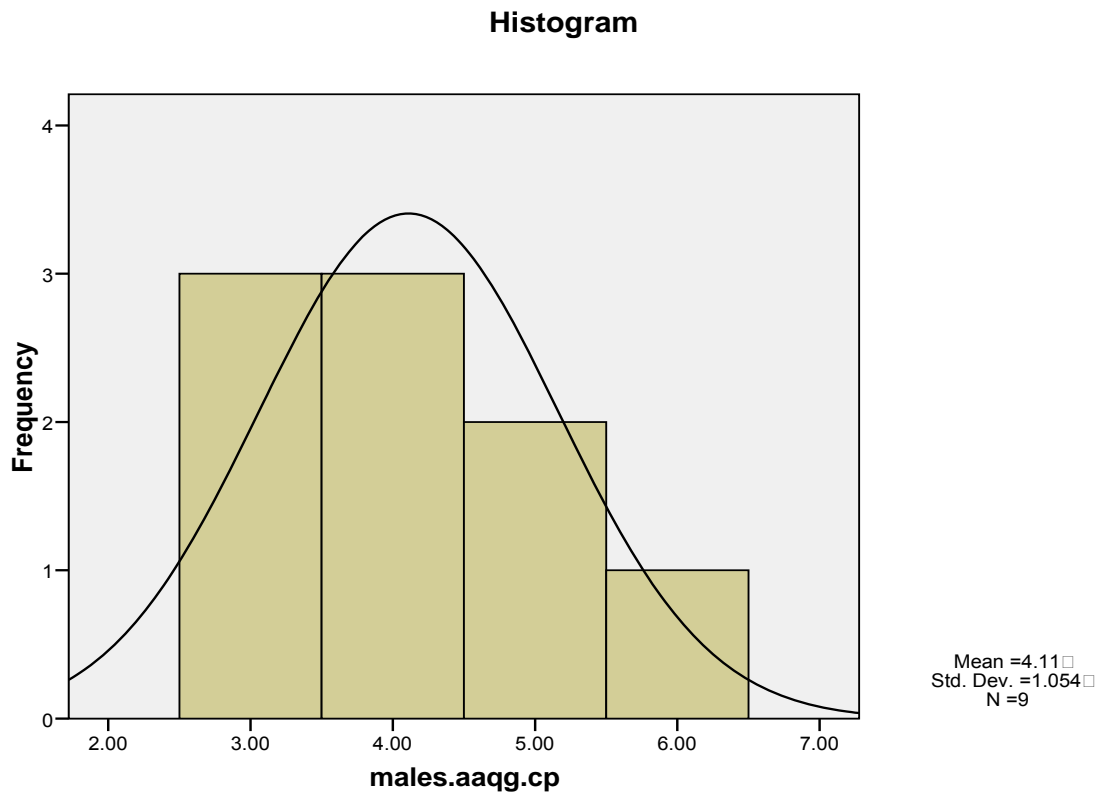
Females indicated more difficulties than males in empathising with their mothers needs. As with the Availability scores, this may be due to the larger numbers of adolescent females in the cohort and to the strain that this developmental stage can place on the mother-daughter relationship (Steinberg,1990).

Social support

Just under half of the children in the current research indicated unsatisfactory social support (45.6%). Looking at females' and males scores' separately, an interesting picture emerges.

Figure 35: Line chart to illustrate females' and males' scores on the Social Support Questionnaire
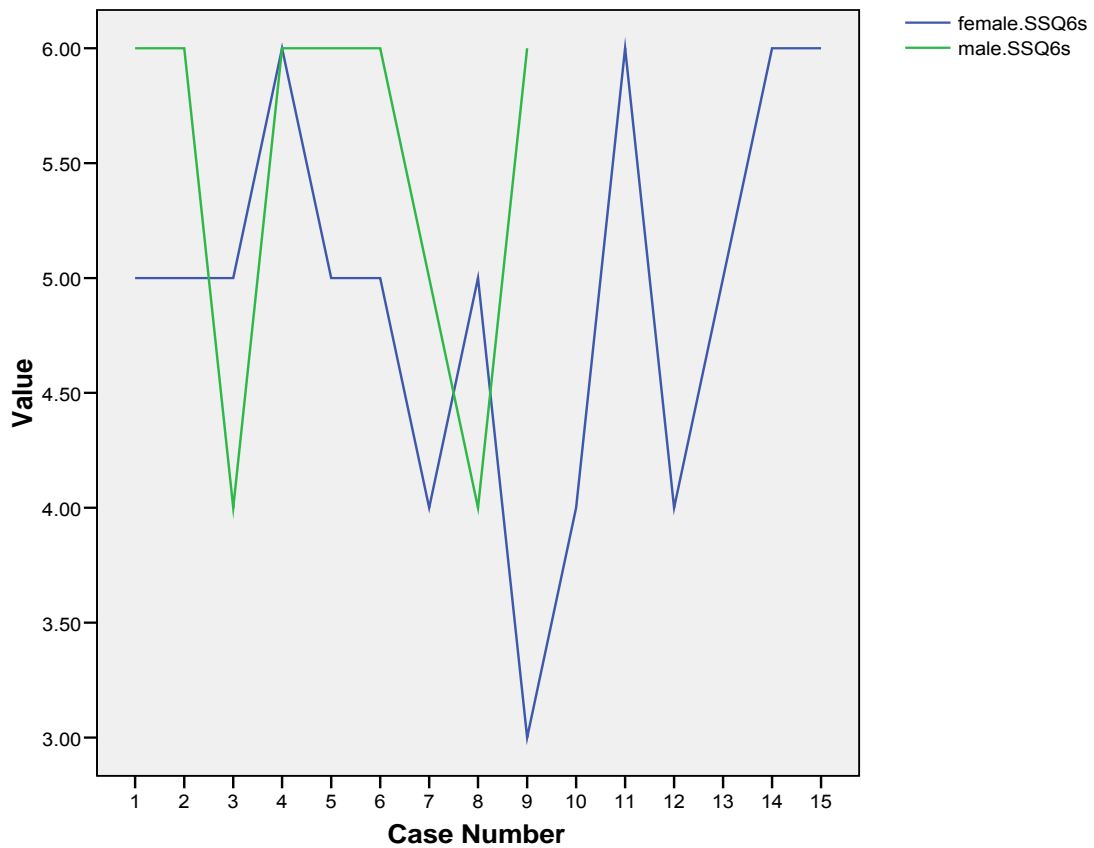
The females in the cohort reported lower levels of social support than males. This is also illustrated in figures 36 and 37 below.

Histogram

female.SSQ6s

Mean =4.93
Std. Dev. =0.884
N =15
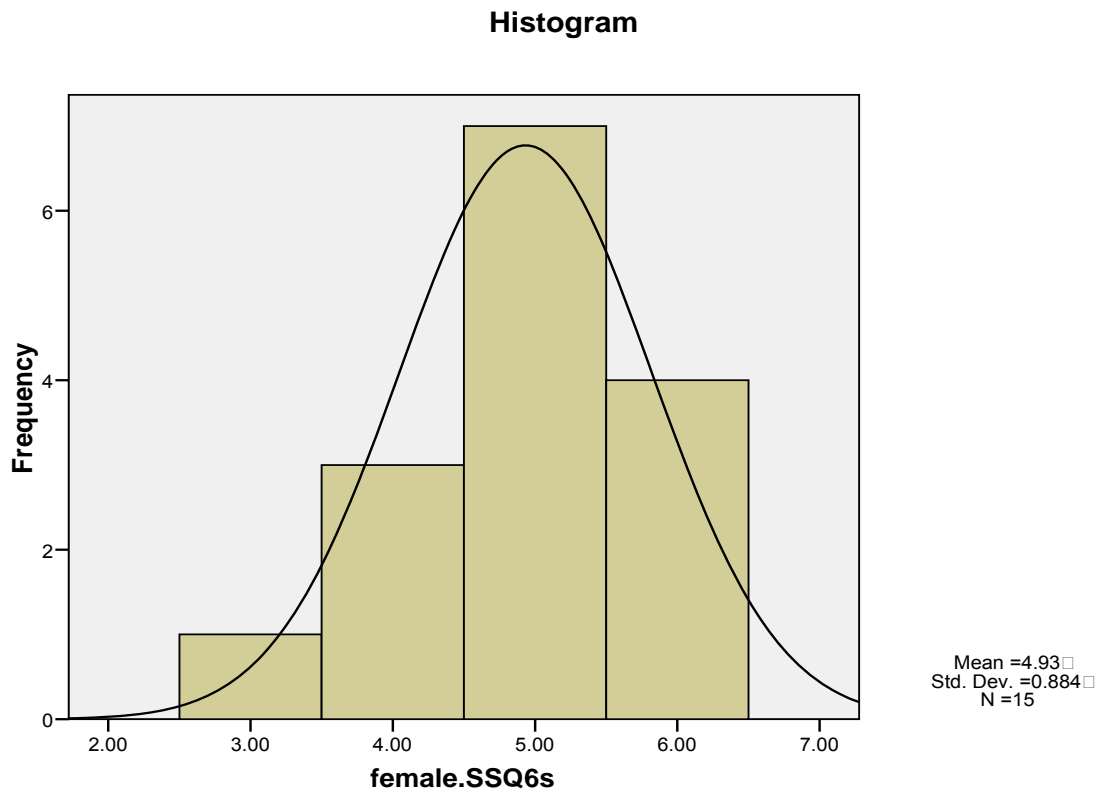
Histogram
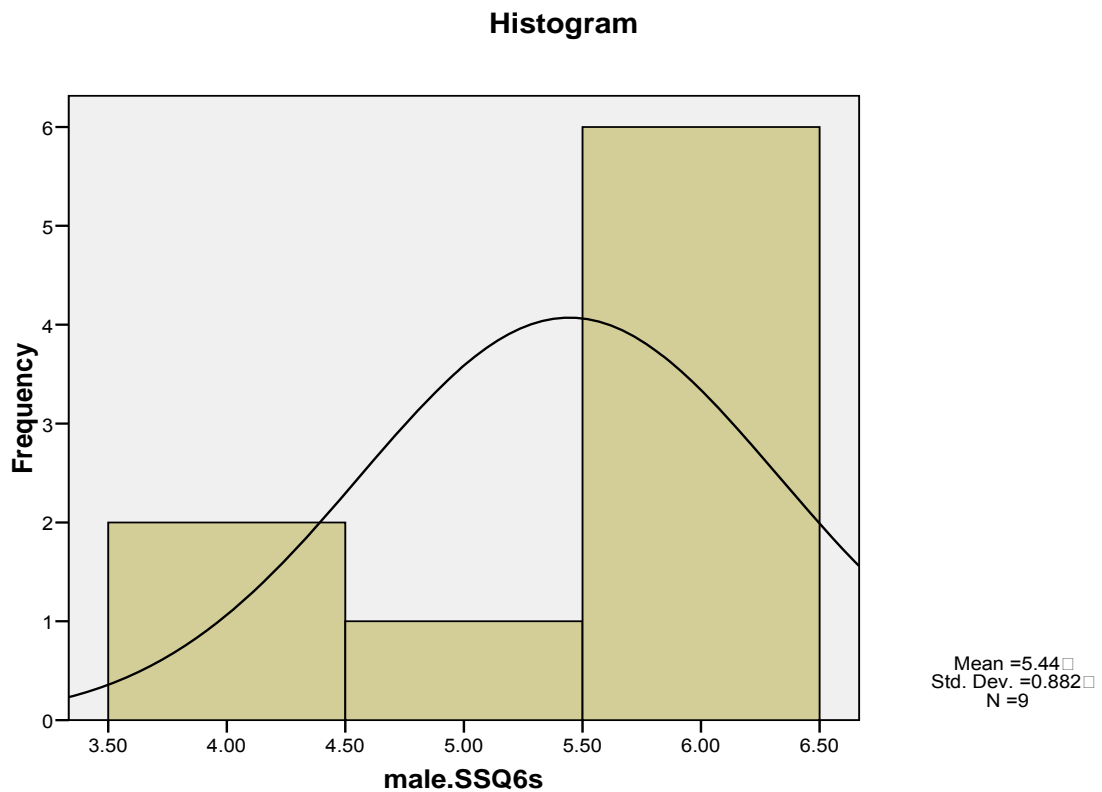
This finding was unexpected, as typically females tend to seek out relationships as a way of coping (Jordan, 2006). It would be expected that they report higher levels of social support than males, not less.

As Jordan (2006) explains, women's coping styles are more relational, where sharing emotional problems is valued. Males, on the other hand, tend to cope with distress by problem-solving: taking action to solve issues and seek strategies (Jordan, 2006).

However, females in this study reported higher levels of attachment difficulties than males. As Sarason *et al.* (1983) and Mukulincer *et al.* (2003) have pointed out, the nature of a child's primary attachment experience shapes their ability to seek and utilise subsequent social support. Consequently, it follows that where there are increased difficulties in the primary attachment relationship, there will be lower levels of social support.

Summary

Looking at females' and males' scores separately across the four test measures, some interesting differences emerge.

Overall, males reported higher levels of self-esteem and social support than females. They also reported lower levels of perceived stigma and attachment-related problems.

This may in part be due to the inclusion of older females in the cohort (males' age range 8-12 years old, females' age range 8-16 years old). Adolescence is a time of emotional turmoil and this may have been reflected in the female scores.

Both females and males reported the highest number of problems on the Angry Distress subscales of the Adolescent Attachment Questionnaire. This was a particularly interesting finding, as the Angry Distress subscale has been shown to have strong convergent validity with the preoccupied attachment style on the Adult Attachment Interview (West *et al*., 1998).

Hesse (1999) identified that this attachment category strongly associated with Axis-II psychopathology on the DSM-IV (American Psychiatric Association, 1999). As such, this finding might elucidate one of the pathways by which the children of parents with learning disabilities are more vulnerable to mental health problems than the rest of the population.

The next section now turns to the main research questions, where data was analysed using correlations and regressions. This allowed for the causal nature of the relationships between variables to be examined.

4.5 Analysis of relationships among variables: correlation and linear regression

Path analysis was used to investigate whether good attachment to mother could act as a resilience factor, protecting self-esteem from the risk of perceived stigma. Furthermore, the model investigated the relationship between attachment characteristics and social support, the latter of which has also been demonstrated to promote resilience.

Small sample size can create erroneous statistical significance in correlation. Every reasonable step was therefore taken to establish the significance of the effect size seen. Observed r values were checked against a critical value table for Pearson's r, which takes account of sample size. Within regression, the positive bias in r^2 was addressed by adjusted r^2. The beta coefficient was also examined to inform effect size. Finally, a statistical power test was carried out on the statistics for each research question.

First, bivariate Pearson's correlation coefficient was carried out on the data to establish statistically significant relationships between variables. Second, linear regression analyses were carried out to examine the proportion of variation that can be accounted for by the regression of one variable on another - the percent of the variance explained, or r^2. Even with small sample size, the proportion of variance found, or effect, is not diminished by small sample size. Therefore, this is a reliable indicator of the causal nature of endogenous variables proposed within the path analysis model.

The Pearson's correlation and the linear regression were performed on the data using SPSS. **(See appendix P for raw data and Pearson bivariate correlation)**

In total, five research questions were examined using correlation, partial correlation and linear regression.

Research question a)

a) *'Is there a causal relationship between high perception of stigma and lower
    levels of self-esteem?'*

Using a one-tailed test, the bivariate correlation between self-esteem and stigma was r
= -.404, $p < 0.05$. In terms of Cohen's (1988) conventions, this is a moderate
correlation.

The critical value table for Pearson's r for sample size n = 24 – df = 2 indicates r = -
.404 to be significant at the $p < 0.2$ level, suggesting a high degree of statistical
significance when the sample size is adjusted for.

A linear regression was then performed on these two variables to consider the
proportion of variance that can be accounted for by regression of stigma onto self-
esteem.

The scatterplot and regression line below illustrate a negative correlation between
stigma and self-esteem, indicating that where perception of stigma increases, self-
esteem decreases.

Figure: 38 scatterplot and regression line illustrating the relationship between stigma and self-esteem.
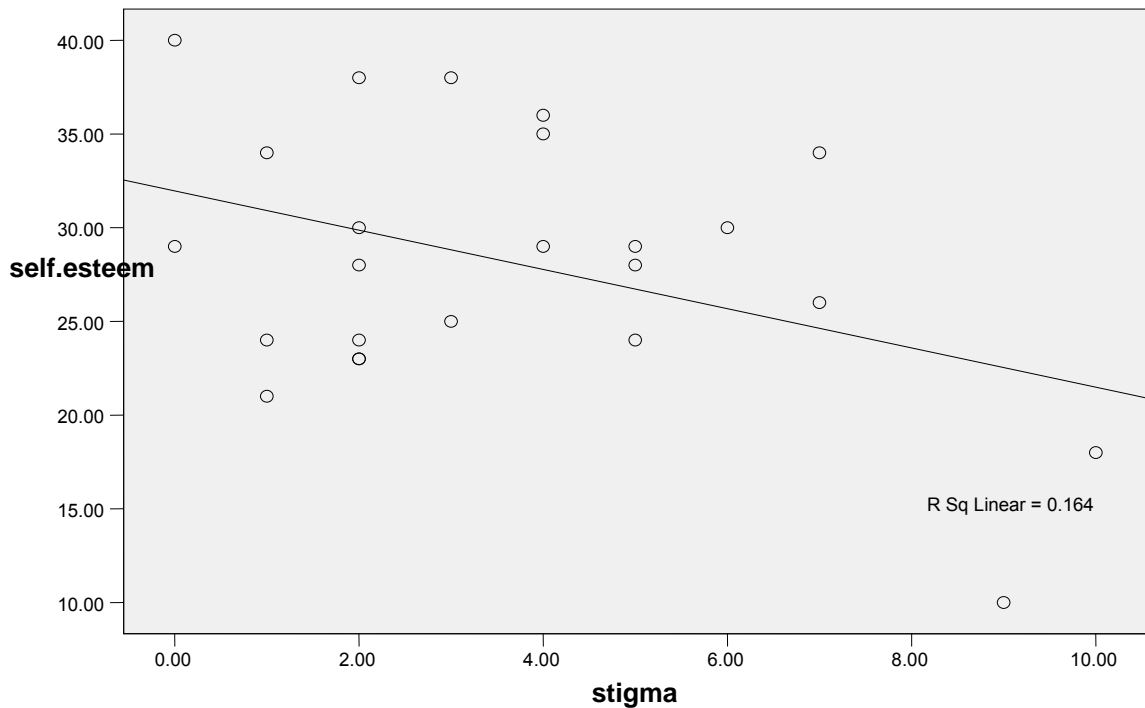
The linear regression performed showed the value of the coefficient of determination is $r^2 = .164$. This means that 16.4% of the variance of scores is accounted for by regression of stigma upon self-esteem.

Because of the small sample size of this study, it is necessary to correct the positive bias in r^2 by adjusted $r^2 = .126$. Therefore, the most reliable estimate of the variance of self-esteem explained by stigma is 12.6%. This would indicate a large effect size, as $r^2 > 10\%$.

The beta coefficient is the estimated average change in the dependant variable (self-esteem) that would be produced by a positive increment of one standard deviation in the independent variable (stigma). For the regression of stigma upon self-esteem $\beta = -.404$ (95% CI – 2.094 to .000).

Therefore, it can be said with 95% confidence level that the average change in self-esteem that would be produced by an increase of one standard deviation in stigma would be approximately 40%; a large effect.

The statistical power for this test, calculated using observed alpha level .05, number of predictors, r^2 and sample size, was found to be 0.515. This indicates that, despite large effect, the statistical power of this test is moderate.

Table F: data for linear regression of stigma onto self-esteem.

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.404(a)	.164	.126	6.53518

a Predictors: (Constant), stigma

ANOVA(b)

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	183.745	1	183.745	4.302	.050(a)
	Residual	939.588	22	42.709		
	Total	1123.333	23			

a Predictors: (Constant), stigma

b Dependent Variable: self.esteem

Coefficients(a)

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	31.962	2.264		14.115	.000
	stigma	-1.047	.505	-.404	-2.074	.050

a Dependent Variable: self.esteem

Consequently, these results provided support for the hypothesis that perceived stigma has a significant causal relationship with low self-esteem. This is in keeping with previous research by Corrigan *et al.* (2006) and (2007) and Wahl and Harman (1989), which indicated perceived courtesy stigma can lead to low self-esteem. Furthermore, as Szalacha *et al.* (2007) point out, this can create a reciprocal feedback loop. Low

self-esteem predisposes a child to further concern about courtesy stigma, which in turn lowers self-esteem.

Research question b)

b) 'Is there a causal relationship between attachment problems and self-esteem?'

Using a one-tailed test, the bivariate correlation between attachment problems and self-esteem was $r = -.663$, $p < 0.01$. In terms of Cohen's (1988) conventions, this indicates a large correlation.

The critical value table for Pearson's *r* for sample size n = 24 – df = 2 indicates $r = -.663$ to be significant at the $p < 0.1$ level, suggesting a high degree of statistical significance when the sample size is adjusted for.

A linear regression was then performed on these two variables to consider the proportion of variance that can be accounted for by regression of attachment onto self-esteem.

The scatterplot and regression line below illustrate a significant negative correlation between attachment-related problems and self-esteem, indicating that where attachment problems increase, self-esteem decreases.

Figure 39: scatterplot and regression line indicating relationship between attachment-related problems and self-esteem
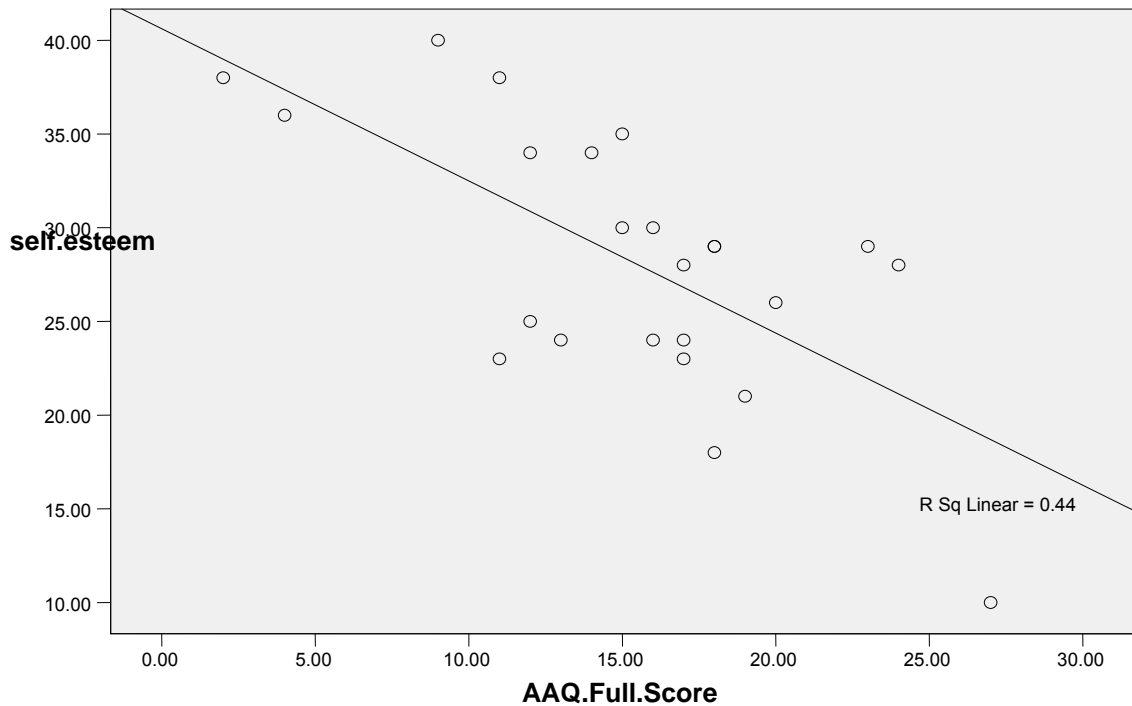
The linear regression performed showed the value of the coefficient of determination is $r^2 = .440$. This means that 44% of the variance of scores is accounted for by regression of attachment problems on self-esteem.

Due to the small sample size of this study, it is necessary to correct the positive bias in r^2 by adjusted $r^2 = .414$. Therefore, the most reliable estimate of the variance of self-esteem explained by attachment problems is 41%. This would indicate a large effect size, as $r^2 > 10\%$.

The beta coefficient for the regression of attachment problems upon self-esteem is $\beta = -.663$ (95% CI -1.217 to -.407). Therefore, it can be said with 95% confidence level that the average change in self-esteem that would be produced by an increase of one standard deviation in attachment problems would be approximately 66%; a large effect.

The statistical power for this test, using observed alpha level 0.5, number of predictors, r^2 and sample size, was found to be 0.978. This indicates the statistical power of this test to be good.

__Table G: data for linear regression of attachment-related problems onto self-esteem.__

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.663(a)	.440	.414	5.34904

a Predictors: (Constant), AAQ.Full.Score

ANOVA(b)

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	493.865	1	493.865	17.261	.000(a)
	Residual	629.468	22	28.612		
	Total	1123.333	23			

a Predictors: (Constant), AAQ.Full.Score

b Dependent Variable: self.esteem

Coefficients(a)

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta	B	Std. Error
1	(Constant)	40.615	3.189		12.736	.000
	AAQ.Full.Score	-.812	.195	-.663	-4.155	.000

a Dependent Variable: self.esteem

These findings confirmed the study's hypothesis that attachment has a causal relationship with self-esteem. This is in keeping with previous research, which has identified that insecure attachment is predictive of low self-esteem (Kim and Cicchetti, 2004). As Emler (2001) demonstrated, the quality of a child's attachment to their parents plays the most significant role in shaping a child's self-esteem, which continues into adolescence and beyond.

Research question c)

c) *'Is there a causal relationship between attachment problems and perception of stigma?'*

Using a one-tailed test, the bivariate correlation between attachment problems and stigma was $r = .370$, $p < 0.05$. In terms of Cohen's (1988) conventions, this indicates a moderate correlation.

The critical value table for Pearson's *r* for sample size n = 24 – df = 2 indicates $r = .370$ to be significant at the $p < 0.25$ level, suggesting a reasonable degree of statistical significance when the sample size is adjusted for.

A linear regression was then performed on these two variables to consider the proportion of variance that can be accounted for by regression of attachment onto stigma. The scatterplot and regression line below illustrate a significant correlation between attachment-related problems and stigma, indicating that where attachment problems increase, perception of stigma increases.

Figure 40: scatterplot and regression line indicating relationship between attachment-related problems and stigma
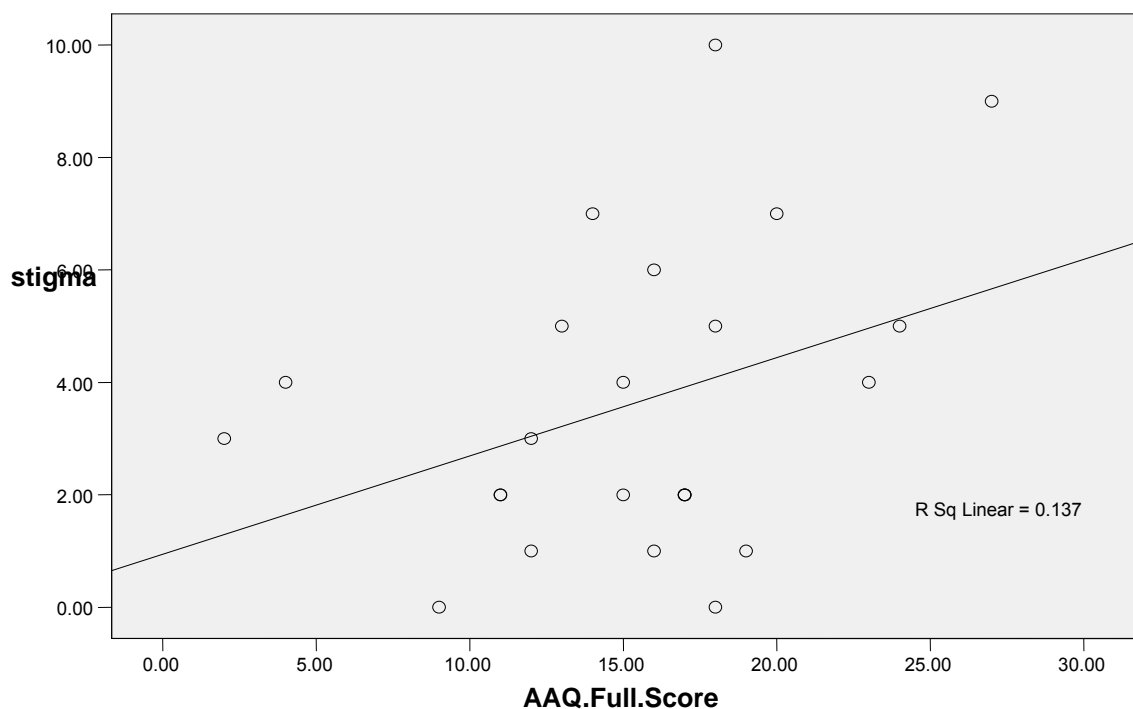
The linear regression performed showed the value of the coefficient of determination is $r^2 = .370$. This means that 37% of the variance of scores is accounted for by regression of attachment problems on stigma.

The small sample size makes it necessary to correct the positive bias in r^2 by adjusted $r^2 = .137$. Therefore the most reliable estimate of the variance of stigma explained by attachment problems is 13%. This would indicate a large effect size, as $r^2 > 10\%$.

The beta coefficient for the regression of attachment problems upon stigma is $\beta = -.370$ (95% CI -.019 to .369). Therefore, it can be said with 95% confidence level that the average change in stigma that would be produced by an increase of one standard deviation in attachment problems would be approximately 37%; a large effect.

The statistical power for this test, using observed alpha level .05, number of predictors, r^2 and sample size, was found to be 0.931. This indicates the statistical power of this test to be good.

Table H: data for linear regression of attachment-related problems onto stigma.

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.370(a)	.137	.097	2.56483

a Predictors: (Constant), AAQ.Full.Score

ANOVA(b)

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	22.902	1	22.902	3.481	.075(a)
	Residual	144.723	22	6.578		
	Total	167.625	23			

a Predictors: (Constant), AAQ.Full.Score

b Dependent Variable: stigma

Coefficients(a)

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta	B	Std. Error
1 (Constant)	.944	1.529		.618	.543
AAQ.Full.Score	.175	.094	.370	1.866	.075

a Dependent Variable: stigma

These results suggest that attachment-related difficulties have a causal relationship with perception of stigma. While no previous research was found which has specifically investigated this issue, it seems logical that the quality of attachment to primary caregiver is likely to influence a child's expectations of others (Howe, 2005).

Some guidance on this point is found in the research on people exposed to racism, which suggests that the *attribution* an individual makes with regards to the discrimination is an important variable in determining the degree to which this experience is damaging.

For example, Szalacha *et al.*'s (2007) report found that people tended to minimise perceived discrimination where there was ambiguity about the perpetrator's motives. If they could attribute the reason for the behaviour to a factor other than their status, they tended to do so. This reluctance on the part of stigmatised groups to perceive discrimination was seen to function as a protective factor.

It seems plausible that the quality of a child's attachment to their primary care-giver is likely to set up expectations as to how they expect others to behave. Therefore, children with secure attachment are less likely to predict that others will be derogatory towards them and, even where discrimination does occur, are more likely to look for alternative explanations than being stigmatised.

Thus, it follows that a child's attachment may play a role in attribution of discriminatory experiences. It appears that children with increased attachment problems are more vulnerable to the perception of stigma. These findings confirmed the current study's hypothesis that attachment style has a causal relationship with stigma.

Research question d):

d) *'Is there a causal relationship between attachment problems and low levels of social support?'*

Using a one-tailed test, the bivariate correlation between attachment problems and social support was $r = -.557$, $p < 0.01$. In terms of Cohen's (1988) conventions, this indicates a large correlation.

The critical value table for Pearson's *r* for sample size n = 24 – DF = 2 indicates $r = -.557$ to be significant at the $p < 0.2$ level, suggesting a high degree of statistical significance when the sample size is adjusted for.

A linear regression was then performed on these two variables to consider the proportion of variance that can be accounted for by regression of attachment onto social support. The scatterplot and regression line below illustrate a significant correlation between attachment-related problems and social support, indicating that where attachment-related problems increase, level of social support decreases.

Figure 41: scatterplot and regression line indicating relationship between attachment-related problems and social support
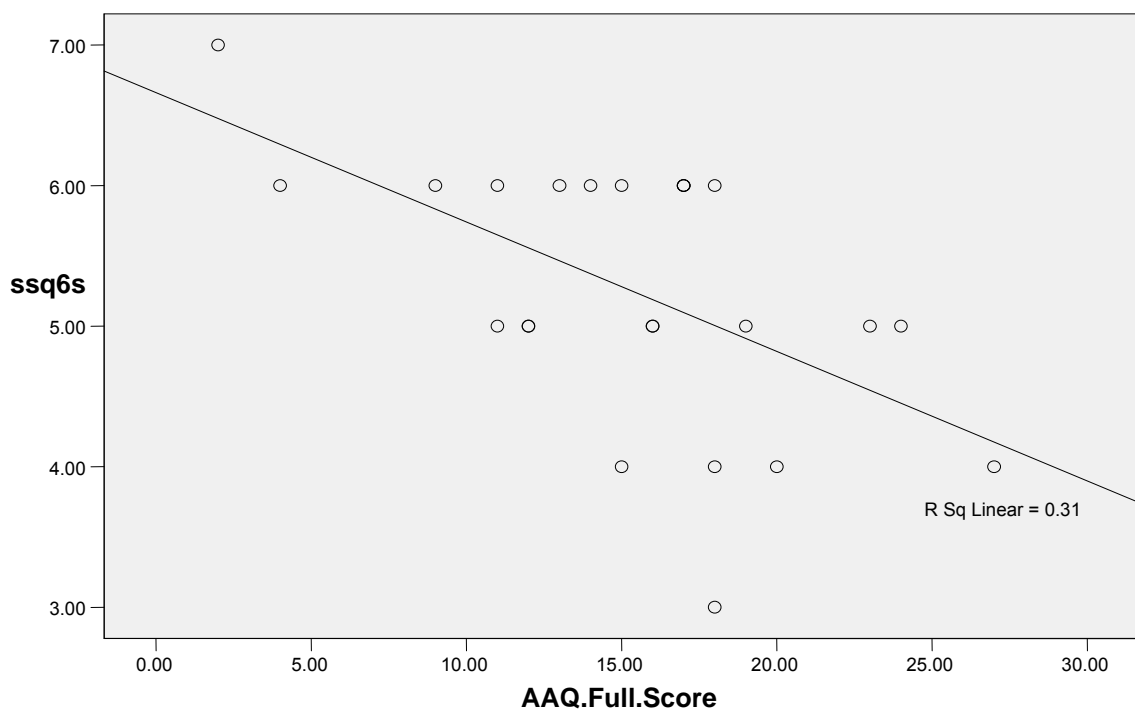
The linear regression performed showed the value of the coefficient of determination is $r^2 = .310$. This means that 31% of the variance of scores is accounted for by regression of attachment problems on social support.

Due to the small sample size of this study, it is necessary to correct the positive bias in r^2 by adjusted $r^2 = .279$. Therefore, the most reliable estimate of the variance of social support explained by attachment problems is 27%. This would indicate a large effect size, as $r^2 > 10\%$.

The beta coefficient for the regression of attachment problems upon social support was $\beta = -.557$ (95% CI -.153 to -.031). Therefore, it can be said with 95% confidence level that the average change in social support that would be produced by an increase of one standard deviation in attachment problems would be approximately 55%; a large effect. The data for this linear regression is shown in Table I below.

The statistical power for this test, using observed alpha level .05, number of predictors, r^2 and sample size, was found to be 0.855. This indicates that the statistical power of this test is good.

Table I: data for linear regression of attachment problems onto social support.

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.557(a)	.310	.279	.80188

a Predictors: (Constant), AAQ.Full.Score

ANOVA(b)

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	6.354	1	6.354	9.881	.005(a)
	Residual	14.146	22	.643		
	Total	20.500	23			

a Predictors: (Constant), AAQ.Full.Score

b Dependent Variable: ssq6s

Coefficients(a)

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta	B	Std. Error
1 (Constant)	6.662	.478		13.935	.000
AAQ.Full.Score	-.092	.029	-.557	-3.143	.005

a Dependent Variable: ssq6s

The negative correlation between attachment problems and social support was large, as was expected (r = -.557). A similarly large effect was seen in the linear regression, which indicated that attachment characteristics accounted for 27.9% of the variance in social support (adjusted r^2 = .279).

Furthermore, the beta coefficient confirmed that an increase of one standard deviation attachment problems would result in an average change of 55.7% in social support (β = -.557).

Consequently, these results found that attachment has a causal relationship with level of social support.

This is in keeping with previous observations by researchers such as Sarason *et al*. (1987), who pointed out that the nature of a child's original attachment style is likely to impact on their ability to generate and make use of emotional support.

Mikulincer *et al*. (2003) clarify this issue by explaining that different attachment styles can influence the level of social support an individual may seek. Thus, children with secure attachment style are likely to have predicted that those around them will be available in times of distress. Conversely, those with insecure attachment tended to exaggerate threat and hold negative beliefs about other people, making it less likely that they will seek support (Mikulincer *et al.*, 2003).

Although resilience research has identified supportive relationships as protective factors for children facing hardship, the current study suggests that seeking such support in times of need may be less likely for those whose original attachment experience has been positive.

In such cases, the attachment 'blueprint' will have shaped children's assumptions about the extent to which others will be there to help them in times of difficulty.

Research question e):

e) *'Do attachment problems moderate the relationship between stigma and self-esteem?'*

Using a one-tailed test, the bivariate correlation between stigma and self-esteem was r = -.404, $p < .050$. In terms of Cohen's (1988) conventions, this indicates a large correlation.

The critical value table for Pearson's r for sample size n = 24 – df = 2 indicates r = -.404 to be significant at the $p < 0.2$ level, suggesting a high degree of statistical significance when the sample size is adjusted for.

A partial correlation was then performed on stigma and self-esteem, controlling for attachment problems. This showed r = -.229, indicating that, where attachment problems are removed from the relationship between perceived stigma and self-esteem, the relationship between stigma and self-esteem is no longer significant.

Table J: data for partial correlation between stigma and self-esteem, controlling for attachment problems.

Correlations

		self.esteem	Stigma
self.esteem	Pearson Correlation	1	-.404(*)
	Sig. (1-tailed)		.025
	N	24	24
stigma	Pearson Correlation	-.404(*)	1
	Sig. (1-tailed)	.025	
	N	24	24

* Correlation is significant at the 0.05 level (1-tailed).

Descriptive Statistics

	Mean	Std. Deviation	N
self.esteem	28.1667	6.98860	24
stigma	3.6250	2.69964	24
AAQ.Full.Score	15.3333	5.70786	24

Correlations

Control Variables			self.esteem	stigma
AAQ.Full.Score	self.esteem	Correlation	1.000	-.229
		Significance (1-tailed)	.	.147
		df	0	21
	stigma	Correlation	-.229	1.000
		Significance (1-tailed)	.147	.
		df	21	0

These findings suggest that attachment affects the strength of relationship between stigma and self-esteem. Children with more secure attachment reported higher levels of self-esteem and lower levels of perceived stigma. Consequently, these findings support the study hypothesis that secure attachment acts as a resilience factor that protects self-esteem from the risks posed by courtesy stigma.

This finding is in keeping with previous research, which has established secure attachment as a resilience factor for children facing adversity (Collishaw *et al*., 2007; Kim and Cicchetti, 2004; Owens and Shaw, 2007).

Summary

In conclusion, the findings of this study supported the path analysis model proposed. The next section therefore demonstrates the main research findings.

4.6 Summary: main research findings

Figure 42: Path analysis model of relationships between variables showing r² and β coefficients
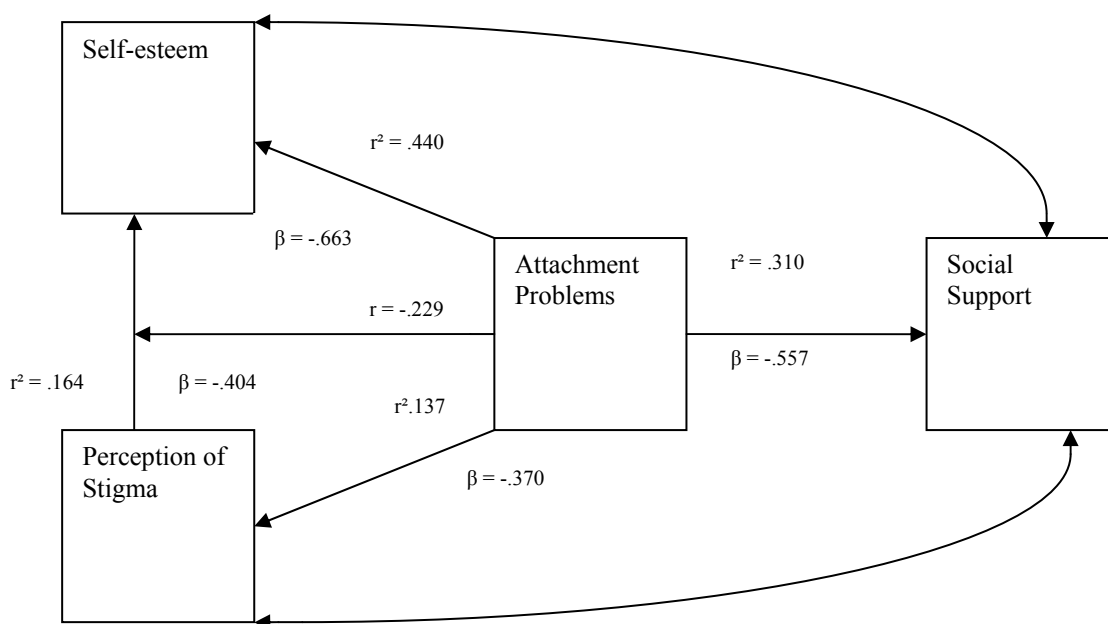
The results of this research confirm the nature of the relationships proposed in the path analysis model. The answers to the research questions were as follows:

- **In answer to research question a:**

The results found a large effect between perception of stigma and self-esteem ($r^2 = .164$; $\beta = -.404$). However, the power of this test was observed to be moderate at 0.515. These findings suggest there is a causal relationship between high perception of stigma and lower levels of self-esteem, but the moderate observed power means this result should be viewed cautiously.

- **In answer to research question b:**

The results found a large effect between attachment problems and low self-esteem ($r^2 = .440$; $\beta = -.663$). The power of this test was observed to be strong

at 0.978. These findings suggest there is there a causal relationship between attachment-related problems and low self-esteem.

- **In answer to research question c:**

The results found a large effect between attachment-related problems and perception of stigma ($r^2 = .137$; $\beta = -.370$). The power of this test was observed to be strong at 0.931. These findings suggest there is a causal relationship between attachment-related difficulties and the perception of stigma.

- **In answer to research question d:**

The results found a large effect between attachment-related problems and low levels of social support ($r^2 = .310$; $\beta = -.557$). The power of this test was observed to be strong at 0.855. These findings therefore suggest there is a causal relationship between attachment problems and low levels of social support.

- **In answer to research question e:**

The results found that attachment-related problems do moderate the relationship between stigma and self-esteem ($r = -.229$).

Summary

While the findings of this research must be treated as exploratory, due to the small sample size, they nonetheless indicate that attachment acts a resilience factor for the children of parents with learning disabilities at risk of courtesy stigma.

These findings are in keeping with research by Collishaw *et al.* (2007), Kim and Cicchetti (2004) and Owens and Shaw (2007), which have established secure attachment as a resilience factor in other at-risk populations.

The next section discusses the results of the current research in the context of the wider literature. In doing so, it highlights the implications for clinical intervention and points the way forward for future research in this area.

Chapter 5: discussion

5.1 Overview

The lives of people with learning disabilities have changed dramatically over the last century. The influence of the normalisation movement (Wolfensberger, 1972) as well as subsequent government legislation, such as the *Disability Discrimination Act* (Office of Public Sector Information, 1995) and *Valuing People: a New Strategy for Learning Disability* (Department of Health, 2001), has promoted the rights of the learning disabled to an ordinary life, including the right to be parents. Increasingly people are choosing to exercise this right; McGaw (1997) estimated that there are approximately 250,000 parents with learning disabilities across the UK.

Evidence remains however that parents do not receive adequate support to help them in their parenting role (Goodinge, 2000; SCIE, 2005). In fact, Brown (1994) believes that, behind the facade of political correctness, society continues to hold negative stereotypes about the ability of people with learning disabilities to be competent parents. Booth (2000) argues that these stereotypes influence the decisions of health and social services professionals, as well as members of the judiciary, in their dealings with parents with learning disabilities on a daily basis, resulting in an over-zealous approach to risk that increases the rate of child removal into care.

In addition to these challenges, there is evidence that people with learning disabilities often struggle with basic parenting skills (Feldman, 1994) and are at increased risk of neglecting their children, most frequently due to omission of appropriate care, rather than abusive intent (McGaw and Newman, 2005). They may be vulnerable to higher rates of mental health problems (McGaw *et al.,* 2007) and are often socially isolated (Llewellyn and McConnell, 2002). It is against this backdrop that approximately half of the children born to parents with learning disabilities are removed into care (Booth *et al*., 2005).

There is a dearth of research into outcomes for the children of parents with learning disabilities (*Good Practice Guidance on Working with a Parent with a Learning Disability*: Department of Health, 2007). In fact, the literature review conducted in this research identified only nine studies that had considered emotional, social or psychological outcomes (Booth and Booth, 1997; Feldman *et al*., 1985; Feldman and Walton-Allen, 1997; Gillberg and Geijer-Karlsson, 1983; Kohler and Didier, 1974; McGaw *et al.,* 2007; O'Neill, 1985; Perkins *et al*., 2002; Ronai, 1997).

This empirical research demonstrates a number of methodological weaknesses, but suggests that these children are at risk of developmental difficulties (Feldman *et al.,* 1985; Feldman and Waltion-Allen, 1997), psychological and social problems (Gillberg and Geijer-Karlsson, 1983; McGaw *et al*., 2007), problems within the parent-child relationship (Kohler and Didier, 1974; O'Neill, 1985; Perkins *et al*., 2002) and maltreatment (Booth and Booth, 1997: Ronai, 1997).

In addition, the literature suggests that the children of parents with learning disabilities may be vulnerable to courtesy stigma (Goffman, 1963), which arises out of simply being the son or daughter of a person with a stigmatised social status (Booth and Booth, 1997; Perkins *et al.,* 2002; Ronai, 1997).

Some research has suggested that courtesy stigma may have a negative impact upon self-esteem (Corrigan *et al*., 2006; Wahl and Harman, 1989). This is of concern as numerous studies have found low self-esteem to predict negative outcomes in childhood and in later life (Emler, 2001).

The aim of the current study was to establish what factors may protect self-esteem from the risks posed by courtesy stigma. In doing so, it drew on the literature from resilience theory (Masten, 2001).

Resilience theory differs from the traditional approach to child development, which has tended to contrast normal and abnormal behaviour patterns. Instead, a resilience conceptualisation of the individual seeks out strengths and opportunities to capitalise on, in order to help children rise above potentially damaging life experiences (Hill *et al*., 2007).

Although to date only one study has investigated resilience in the children of parents with learning disabilities (Booth and Booth, 1997), studies with other vulnerable populations have identified a number of important protective variables for children facing adversity (Masten, 2001). The current study drew out five potential resilience factors that may be pertinent to the children of parents with learning disabilities: attachment, social support, age of the child, gender and cognitive ability. It then closely examined the role of attachment to mother and social support as resilience factors.

Twenty-four children were identified. Two main exclusion criteria were used in order to control for the number of variables under examination:

- Children who had learning disabilities themselves were excluded, as they may have been subject to primary stigma as a result of their learning disabled status, in addition to courtesy stigma as a result of association with their parent. Excluding those who may have been subject to primary stigma allowed for a more careful examination of courtesy stigma.

- Children being monitored under child protection plans at the time of the study were also excluded, as a number of such children may have been subject to abuse and/or neglect by their mother, which could lead to insecure attachment (Howe, 2005). As this research was concerned with the potential for a secure attachment relationship to act as a resilience factor, excluding children where there may already be insecure attachment reduced the number of variables under examination.

In effect, the families who took part in this study represent the success stories, the ones that had managed to stay together despite adversity. However, these families do not exist in large numbers in any one area of the country, nor are they necessarily known to services. In order to generate as many research participants as possible, this study therefore recruited from nine different NHS trusts and four charitable organisations across England. In total twenty-four children were identified, in Newcastle, London, Bristol, Wales, Somerset, Devon and Cornwall.

Ultimately, this research sought to provide a baseline, by isolating some of the protective factors that foster well-being in those children who were doing relatively *well* in the care of their learning disabled parent, i.e., those who had *not* been removed into care, were *not* subject to child protection, did *not* have a learning disability and were in mainstream school.

If protective factors can be isolated in a systematic way, counselling psychologists and other professionals working with such children may be able to target specific variables for intervention. This could not only facilitate intervention to prevent parenting failure (and therefore poor child outcomes), but provide a focus for those children not doing so well, who may already be monitored under child protection plans or have been removed into care.

5.2 Key research findings

Children

The study used a path analysis model to assess attachment and social support as resilience factors, reducing the impact of perception of stigma upon self-esteem. The relationships between variables were examined for causality using Pearson's product-movement correlations and linear regression.

The relationship between perceived stigma and self-esteem

In total, 16.7% of children reported a high level of perceived stigma. Perception of stigma was found to have a casual relationship with self-esteem ($r^2 = .164$; $\beta = -.404$); these findings are in keeping with previous literature which has suggested a relationship between courtesy stigma and low self-esteem (Corrigan *et al.*, 2006; Wahl and Harman, 1989). As such, the 16.7% of children who reported a significant level of perceived stigma may have been vulnerable to risks to their development, via the threat posed to self-esteem.

Self-esteem can be negatively effected by courtesy stigma, as our attitude towards ourselves is derived from how we believe others view us (Emler, 2001). This is not necessarily determined by how people treat us, but how we imagine we are perceived. Consequently, where a child sees themselves as stigmatised by association, it seems possible this discredited identity may influence self-worth.

We also gain self-esteem from the social identity of the group to which we belong (Tajfel, 1978). If children associate themselves with their parents' discredited group status, the risk of perceived stigma increases. However, it may be that children avoid within-group identity, as a way of trying to manage courtesy stigma (Birenbaum, 1970), particularly if not learning disabled themselves. This may leave them without a clear sense of belonging, to either the disabled or non-disabled groups in society, which could also negatively impact upon self-esteem.

Attachment and social support as resilience variables

Most significantly, this research found attachment acted as a moderating variable in the relationship between stigma and self-esteem ($r = -.229$). This suggested that good attachment may act as a resilience factor for children at risk of courtesy stigma.

Indeed, it was notable that 20.8% of children reported attachment problems and 16.7% reported high levels of perceived stigma; figures approximately in keeping with each other. If attachment acts as a resilience to courtesy stigma, it should be that these figures are comparable - it would only be those with poor attachment who would be expected to report higher levels of stigma.

The findings of this study were therefore consistent with those of Owens and Shaw (2007), Kim and Cicchetti (2004) and Collishaw *et al.* (2007), which identified secure attachment as a resilience factor for children at risk of adversity.

Attachment was found to have a casual relationship with social support ($r^2 = .310$; $\beta = -.557$). Children who reported lower levels of social support also reported higher levels of attachment-related difficulties; the level of social support was in effect a by-product of attachment style. This was in keeping with Collishaw *et al.* (2007), Sarason *et al.* (1987) and Mukulincer *et al.* (2003), who have suggested that the nature of a child's primary attachment may impact on their ability to seek out further relationships. As such, children with insecure attachment may be at greater risk of poor social support.

Overall, almost half the sample (45.6%) reported unsatisfactory levels of social support. They also tended to report family as emotional supports, rather than friends. This was in keeping with Booth and Booth (1997), who found approximately one third of their participants reported few friendships outside of the family. This is of particular concern, as good peer relationships have been found to promote resilience for children experiencing adversity (Bolger and Patterson, 2001a; Bolger *et al.,* 1988; Schwartz *et al.*, 2000).

For the 16.7% of the sample who reported high courtesy stigma, a complex issue may compound this scarcity of same-age relationships. Those who feel stigmatised may

be less likely to develop friendships, as a sense of 'otherness' is experienced, possibly limiting the opportunities for friendship to develop (Angermeyer *et al*., 2003; Birenbaum, 1970; Burk and Sher, 1990; Green *et al.*, 2005; Mehta and Farina, 1988; Ostman and Kjellin, 2002). As such, perceived stigma may influence the nature of a child's social support system; relationships sought within the family network rather than from peers.

The current study identified that children with greater attachment difficulties reported higher levels of perceived stigma. Thus, attachment was found to have a causal relationship with levels of perceived stigma ($r^2 = .137$; $\beta = -.370$). This finding was opposite to that identified by Perkins *et al.* (2002), who reported a significant relationship in the other direction (that is, low levels of perceived stigma predicted secure attachment). However, the findings of the current study are consistent with the wider literature, which suggests the quality of a child's attachment to their primary care-giver will influence their expectations of others (Howe, 2005). It is likely therefore those children with insecure attachment are at greater risk of internalising the meaning of their parents' discredited social status.

Attachment was seen to have a causal relationship with self-esteem ($r^2 = .440$; $\beta = -.663$); children with insecure attachment to their mother reported lower levels of self-esteem. This was in keeping with previous research, which has found insecure attachment predicts lower levels of self-esteem (Kim and Cicchetti, 2004).

Age of the child as a resilience factor
Interestingly, no significant differences were seen between younger children's and adolescent's scores on the Perception of Stigma measure. This may suggest that some children are potentially vulnerable to perceived stigma from an early age.

This finding is not consistent with previous research; Szalacha *et al.* (2007) found perception of stigma tends to increase with age. However, their study was carried out with children vulnerable to racial discrimination. There is a qualitative difference between this and courtesy stigma, which arises out of being associated with a learning disabled parent. The children of parents with learning disabilities, when they are of average intelligence themselves, have been found to take over their parent's role in

the family (O'Neill, 1985); in essence, becoming carers to their mother. This possibly exacerbates perception of stigma (Wahl and Harman, 1989) and self-stigma (Corrigan *et al.*, 2006) in a way that racial discrimination does not.

In this research, a child's age was not therefore seen to play a role in resilience.

Intelligence as a resilience factor

The literature has suggested that at least average intelligence can act as a resilience factor for children faced with adversity (Cicchetti and Rogosch, 1997; Flores *et al.*, 2005; Herrenkohl *et al*, 1994).

Children in the current study demonstrated IQ scores which ranged between 77 (borderline IQ range) and 119 (high average IQ range); their intellectual functioning showed a large standard deviation (10.1). However, no significant relationship was found between IQ and self-esteem in the current study, suggesting that IQ could not account for adaptive functioning in the participants.

The influence of gender in resilience

In the current research females reported higher levels of perceived stigma and lower levels of self-esteem than males. Their higher levels of perceived stigma may be attributable to greater attachment problems; as insecure attachment is likely to influence expectations of others and as such might exacerbate self-stigma. Their lower levels of self-esteem may partly be explained by gender. Research has shown that females are more prone to internalise distress, leading to negative self-appraisal (Fergusson and Horwood, 2007). A number of females in this study may therefore have internalised a sense of their parents discredited social status, effecting self-esteem.

Self-esteem may have also been influenced by the age of the participants, as all adolescents were female. This suggestion has been made in the literature, for example, Kling *et al.* (1999) found adolescent females tend to report lower levels of self-esteem than males.

The findings of the current research suggest that gender may influence the nature of resilience for the children of parents with learning disabilities.

Other gender differences

Some further interesting differences between male and female scores were observed:

- There were significantly more females (62.5%) than males (37.5%) in the cohort.

Although the sample size of this study is not large enough to draw any firm conclusions, it is possible that this may reflect a higher number of males subject to child protection plans (and who were therefore excluded from this research). Indeed, this suggestion is in keeping with Vincent (2008), who found a prevalence rate of 51% males versus 49% females monitored under child protection in the wider population of at-risk children in England. It may be that this difference is even greater for the children of parents with learning disabilities. Feldman and Walton-Allen (1997) identified that behavioural disorders are particularly high amongst sons of such parents - perhaps resulting in them coming to the attention of schools and services more quickly and more frequently than females. This issue needs further exploration in future research.

- Females reported higher levels of attachment problems and lower levels of social support than males.

This may be because the mother-daughter relationship can be particularly strained during adolescence, when the parental relationship normally gives way to attachment to peers (Steinberg, 1990). However, it was notable that none of the adolescent females in the current study displayed such a shift to peer group attachment. In fact, their scores indicated a *lack* of same-age relationships. It may be, for females who participated in this study, their adolescence was characterised by a deficit of available relationships to meet their needs, generating increased hostility towards their mothers. Furthermore, given that females in the cohort reported a higher rate of attachment problems, it is in keeping that lower levels of social support were reported: there is a

strong association between an individual's original attachment style to their main care-giver and their ability to seek wider social support in subsequent relationships (Sarason, 1983).

Measures

On the Perception of Stigma Questionnaire, 16.7% of children reported a high level of perceived stigma in relation to their mother. Although a small percentage of the overall sample, this indicates a number of children at risk of courtesy stigma as a result of their parent's social status. However, it should be noted that issues of validity with the Perception of Stigma Questionnaire may have effected children's outcomes on this measure (discussed further under section 5.5, p.246). It is possible that the prevalence of courtesy stigma was in fact more significant than these results would suggest.

In this study's cohort of twenty-four children, approximately one fifth (20.8%) reported significant attachment problems on the Adolescent Attachment Questionnaire. This is lower than the established distribution pattern of attachment style in normal populations, where generally one-third is insecure and two-thirds is secure (van IJzendoorn *et al.*, 1999).

This may be explained by the sample, which was heavily biased. The mothers recruited to the study were all known to services. Therefore, given the scrutiny these particular women were parenting under, they were likely to be operating at the robust end of the attachment continuum.

Nonetheless, the 20.8% of children who did report significant attachment problems did so largely on the Angry Distress subscale of the Adolescent Attachment Questionnaire. This subscale taps the extent to which a child feels hostility and frustration towards their mother as a result of their unmet attachment needs.

It is not possible to know from the findings if this is a characteristic of learning disabled parenting and so further research is needed in this area. However, it seems plausible that even a highly effective mother with a cognitive impairment may struggle to meet all of her child's attachment needs – for example, anxiety over school

homework may not be assuaged by a mother more intimidated by the task than the child.

The Angry Distress subscale of the Adolescent Attachment Questionnaire has been shown to have strong convergent validity with the preoccupied attachment style on Main's (1985) Adult Attachment Interview (West *et al.*, 1998), the gold standard in adult and adolescent attachment measures (Cassidy and Shaver, 1999). It is interesting to note therefore that Hesse (1999) reports a significant association between preoccupied attachment on the Adult Attachment Interview and Axis II classification in DSM-IV (American Psychiatric Association, 1999).

Consequently, these children's elevated Angry Distress scores may indicate risk for psychopathology in later life. If this is so, then there are implications for intervention, as children with this attachment profile could be targeted for support at an early stage.

On the Social Support Questionnaire, children were invited to list peer relationships and other friendships outside of the family. Where children were unable to do this, as they were unable to identify nine friendships, they were asked to list supportive others from within the family network. This included father and mothers' boyfriend. However, many chose to also list their pets as emotional supports. While this raised obvious questions, nonetheless, the literature suggests that pets can have an important role to play for vulnerable children. For example, Hart *et al.* (2007) point out that those children who experience neglectful and/or abusive experiences may find it easier to attach to a pet than to another human being. In fact, Mallon (1992) draws attention to the fact that the actual *process* of attaching emotionally to a pet can have a therapeutic advantage for vulnerable children. Therefore, while on the surface one may think that pets have no importance in terms of supportive type relationships, the literature indicates that they can be valuable simply by virtue of that which they enable a child to feel towards them.

Mothers

Mothers' scores on the ABAS-II, the adaptive behaviour measure, indicated that their mean level of competence in this regard was low (mean 59.9; range 48-75). This was surprising, as adaptive behaviour has been shown to be a more relevant indicator of parenting ability than IQ (Budd and Greenspan, 1984) and all of the mothers in this cohort were acting as main carers for their children. On the basis of their ABAS-II scores, it should have been the case that some of these mothers were struggling to provide adequate care for their children.

The fact that 87.5% of the mothers in this research were in a stable relationship probably may explain why their lack of adaptive behaviour skills had not already resulted in their involvement with child protection agencies. Evidence has shown that the presence of a supportive relationship can actually protect against parenting failure (Seagull and Scheurer, 1986).

Furthermore, none of the children in this study had a learning disability themselves. It may be that, in some cases, they had learnt to compensate for their mother's deficits in day-to-day living skills. Indeed, research has shown that where a child's IQ is higher than that of their parents, they may become precociously mature (O'Neill, 1985).

5.3 Implications for intervention

This study has demonstrated that a secure attachment relationship to the primary care-giver can act as an important protective factor, which can promote good self-esteem despite risks to development.

Yet, there are several reasons why mothers with learning disabilities may struggle to provide the conditions necessary for their child to form a secure attachment relationship. They are at greater risk of mental health problems than the general population (McGaw *et al.*, 2007), which may impact upon individual functioning generally, and restrict the ability to form an effective bond with their child (Howe, 2005). They are also more likely to be abused by their spouse than other women (Koller *et al.*, 1988), increasing their risk of emotional and psychological difficulties, and potentially compromising the mother-child relationship.

Women with learning disabilities may be more liable to abuse of some form in their own childhoods (McGaw *et al.*, 2007). If perpetrated by their parents, they are vulnerable to insecure attachment in childhood, as well as subsequent, relationships. A mother entering parenthood with such a history may struggle to provide something better for her child (Howe, 2005). Several studies have shown that there is a strong transgenerational transmission of attachment style; van IJzendoorn (1995) reported that where a mother has an insecure attachment style within relationships, there is a 70% chance her child will also develop the same.

It may be therefore that mothers with learning disabilities are particularly vulnerable to a range of stressors, which have the potential to compromise the conditions necessary for their child to form a secure attachment.

In addition to these significant obstacles, people with learning disabilities frequently parent under the scrutiny of social services. Where children are monitored under child protection, mothers' childcare skills may be assessed on an ongoing basis, over

several years in some cases. Such pressure will no doubt further impact on the ability of a parent to provide natural and spontaneous mother-child bonding.

It may be that maternal insecure attachment underpins much of the child neglect that characterises parenting by the learning disabled. Possibly due to insecure attachment and/or mental health problems, the care-giving offered is passive and unresponsive. However, research to date has tended to conceptualise neglectful care-giving in this population as born out of ignorance, the reality of low cognitive ability leaving a parent ill equipped to understand children's developmental milestones or need for cognitive stimulation and emotional availability (McGaw and Newman, 2005). Consequently much of the intervention offered to mothers has focused upon parent skills training, in order to address these knowledge deficits (Feldman, 1994).

The current research suggests a move forward. Interventions designed to address parental attachment history may be helpful in promoting secure mother-child relationships, which in turn will enhance child resilience.

This suggestion is consistent with the findings of Bakermans-Kranenburg *et al*. (2003), who report that attachment-based interventions are effective in promoting child attachment security. Furthermore, these interventions have been found to be effective with families of low socio-economic status, where multiple risk factors (such as poverty and mental health problems) are also present, as is the case for many mothers with learning disabilities.

It is possible that counselling psychologists are deterred from attachment intervention, as there is a belief that such work is costly and protracted. Yet, Bakermans-Kranenburg *et al*. (2003) found that five sessions proved just as successful as sixteen in working with such families, indicating such intervention can facilitate change in relatively few sessions.

Attachment-based intervention focuses largely on mothers, as the development of the attachment relationship is seen to be more heavily related to the behaviour of the primary care-giver than to the child (Bowlby, 1969; 1973; 1980). Its core aim is to help mothers develop insight into their own experience of being parented and to

reflect on how this has shaped their relationship with their children (Bakermans-Kranenburg *et al*, 2003).

However, attachment interventions may also be relevant to foster carers and to adoptive parents, in cases where children have been removed from their learning disabled parent. Although removal into care will inevitably mean attachment trauma has occurred, research shows a significant degree of this damage can be addressed with subsequent consistent and sensitive care-giving. As Bowlby (1969; 1973; 1980) explained, the attachment 'blueprint' created by the experience of the primary caregiver is not set in stone. It is available for constant revision in the face of new attachment experiences.

Research by Dozier *et al*. (2001) illustrates Bowlby's earlier findings. Dozier and colleagues found that infants placed in foster care, after a period of consolidation, organise their attachments around the availability of the new caregivers. Given time, similar levels of concordance are then seen between the foster carer and the child with respect to attachment style. Where consistent, sensitive and reliable care-giving is achieved, the foster carer can replace the biological parent as the primary attachment figure for the child. This would suggest that counselling psychologists could also use attachment-based strategies to facilitate secure attachment between foster or adoptive parents and children placed in their care.

This study found children with insecure attachment reported lower levels of social support than those with secure attachment. Furthermore, it identified that (regardless of attachment security) these children were unlikely to have much by way of emotional support from peer relationships. This is significant, as constructive peer relationships have been established as an effective resilience factor for children faced with adversity (Collishaw *et al.*, 2007; Kim and Cicchetti, 2004; Owens and Shaw, 2007).

This seems to highlight a need for clinical intervention to promote increased peer support for such children. Counselling psychologists might look to help parents understand their children's need for reciprocal friendships. Children may benefit from individual counselling sessions, helping them to develop strategies to forge

friendships. Schools could also be encouraged to identify those who are isolated and provide opportunities for them to join after school clubs etc., increasing their social contact.

The current research found that 16.7% of children reported a significant level of perceived stigma in relation to their mothers' social status. Interventions designed to address such courtesy stigma might focus upon promoting disability awareness in children through classroom education. Support for children might also be given via individual counselling sessions, helping them to understand the discrimination they and their parents may face and develop coping strategies to manage such experiences. In order for children to gain within-group identity (Tajfel, 1978), services to parents with learning disabilities may facilitate children to come together in their own forum, separate from their parents, in a community based facility to minimise further stigmatisation.

5.4 Implications for services

The Department of Health (*Good Practice Guidance on Working with a Parent with a Learning Disability*, 2007), Goodinge (2000), Morris (2003), Olsen and Tyres (2004) and Wates (2002) have all advised that child and adult services should work together to support parents with learning disabilities.

In keeping with this, counselling psychologists could promote effective inter-agency working by providing training to health and social services colleagues on attachment interventions; enabling attachment-based parenting groups to be established.

Counselling psychologists could advise general practitioners as well as midwives and health visitors to use a screening tool to assess maternal attachment style at the pre-natal stage. This would enable services to identify which families are most in need of support.

Such interventions could allow services to focus on preventative strategies to protect against the development of insecure child attachment and poor child outcomes and move away from the crisis-led intervention they have been heavily criticised for by the Social Services Inspectorate (Goodinge, 2000).

Ultimately, if services were to take a preventative approach to intervention, the number of children removed into care may fall. This would have obvious benefits to the child, and significant financial implications for the NHS and social services. As Selwyn *et al.* (2006) illustrate, a child removed into care can cost the statutory services anything up to £150,000 per year.

Services working with parents with learning disabilities and their children should look to address the stigma many face within their communities. Although much has been done to address this at a governmental level through legislation and White Papers such as the *Disability Discrimination Act* (Office of Public Sector Information, 1995), *Valuing People: A New Strategy for Learning Disability* (Department of Health,

2001) and the *Human Rights Act* (Office of Public Sector Information, 1998), evidence suggests these families are still subject to stigmatisation in their day-to-day lives (CHANGE, 2005; *Good Practice Guidance on Working with a Parent with a Learning Disability*: Department of Health, 2007). Local services may raise disability awareness by working in partnership with schools, community centres and leisure facilities, helping the public to better understand the difficulties these families often have to contend with, thereby reducing stigmatisation.

Services should also respond to the criticisms of the Department of Health (*Good Practice Guidance on Working with a Parent with a Learning Disability*: 2007), Goodinge (2000), Morris (2003), Olsen and Tyres (2004), Tarleton *et al*. (2006) and Wates (2002), and ensure professionals are appropriately trained to deliver effective intervention to these families. Furthermore, across the country, CLDT's and children's social services should take responsibility for developing a national strategic approach to planning intervention to parents with learning disabilities, in order that a consistent, evidenced-based approach is taken.

5.5 Critique of methodology

Ethics

Ethical approval for this study was granted by MREC, with the request that mothers should be formally assessed for learning disability using measures of cognitive functioning and adaptive behaviour. This protected the integrity of the research data. Indeed, absence of formal assessment of learning disability is a criticism which can be levied at many of the studies in this field (e.g. Feldman *et al.*, 1992; Llewellyn and McConnell, 2002; Schilling *et al.*, 1982; Sternfert-Krose *et al.*, 2002).

Researching attachment and courtesy stigma with the children of parents who have learning disabilities requires the exploration of sensitive topics and raises ethical dilemmas. Investigating courtesy stigma serves to highlight its existence; a sense of 'otherness' is underlined for families headed by a learning disabled parent. Yet without research an evidence base will not develop and there will remain little guidance for clinical intervention – itself an ethical issue.

These issues are likely to have impacted on the research recruitment process. In total, forty-three families met the research inclusion criteria, yet only twenty-four consented to participate. The most common reason for declining participation was a fear of consequences arising from the researcher assessing their children. A number of mothers could not be reassured that the results were anonymised and for research purposes only.

Such concerns are well established in the field; *Good Practice Guidance on Working with Parents with a Learning Disability* (Department of Health, 2007) draws attention to the fact that parents often mistrust professionals for fear their parenting will be deemed inadequate and their child removed from their care.

In the current study, it was possible that such worries were exacerbated because the researcher was a stranger, rather than someone with whom they had developed a good relationship. It is understandable that some mothers did not want their child to be

assessed, particularly if they were already concerned about professionals' opinions of their parenting abilities.

Such worries could have been minimised if the help of a key contact had been enlisted; someone with whom the mother had an established relationship, in order to carry out data collection. This may have helped foster confidence that the research process was not directly linked to social services or to child protection, as many of the mothers who refused to participate seemed to fear.

Exclusion criteria

There were several exclusion criteria in this research, which further reduced the number of potential participants. The study excluded children who were learning disabled in order to control for the number of variables under examination. Children with learning disabilities themselves may have been subject to primary, as well as to courtesy, stigma. As this research was concerned with the issue of courtesy stigma, this exclusion allowed for a clearer examination of the specified variable. However, in doing so, the study created a biased sample that was not necessarily representative of children of parents with learning disabilities as a whole.

Children involved with child protection were also excluded, as some may have been subject to neglect and/or abuse by their mother, which could possibly lead to insecure attachment (Howe, 2005). This exclusion helped control the number of variables under review, but it should also be noted that approximately half of these children are typically involved with child protection agencies at any one point in time (Booth *et al.*, 2005); this exclusion therefore raises issues about the degree to which the participants were representative of their population.

Sample size

This study was able to recruit twenty-four mothers and their children who met the research inclusion criteria. In terms of quantitative research this is a small sample size and precautions were taken with the data to prevent Type I errors. While previous quantitative studies have drawn on similarly small samples, ranging from n = 12 (Feldman *et al.,* 1985) to n = 58 (McGaw *et al.*, 2007), it also means findings have limited generalisability to the rest of the population.

The universe of potential participants in this kind of research is small and given the difficulties presented by the high level of child removal into care, it is not easy to see how the issue of sample size will alter for research going forward. Perhaps one way investigators may gain access to larger numbers of participants is to carry out studies over many years, allowing for new generations of children to come through. Alternatively researchers in the area could look to co-ordinate their investigations; so fewer, larger studies are carried out, as opposed to a higher number of smaller enquiries.

Recruitment bias

Participants were all recruited via services and were not randomly selected. As a result, mothers may have had particular needs and/or resources not typical of the wider population in question.

Furthermore, parental involvement with services perhaps led to these children being more acutely aware of their mothers' stigmatised social status than they may otherwise have been. Again, this may mean participants were not representative of parents with learning disabilities, or their children, as a whole.

Measures

This study used the Adolescent Attachment Questionnaire (West *et al.*, 1998) to assess mother-child attachment. This measure was considered the most appropriate available at the time of the research, given the study's particular constraints. However, the fact that it does not assign children to a specific attachment category, such as avoidant or disorganised, was a weakness in the research design. More detailed data on attachment category would have been yielded if the Adult Attachment Interview (AAI) (Main, 1985) had been utilised.

The Self-esteem Scale (Rosenberg, 1965) is considered the gold standard in self-esteem measures (Emler, 2001). The nature of the scale means it measures self-esteem as a trait; a stable entity. Yet some researchers have argued that self-esteem would more accurately be seen as a state. Like an emotion, which can fluctuate from week to week, year to year, depending on the interactions the individual has with others (Leary *et al.,* 1995). If this is so, then the self-esteem of children in this study

should not be seen as a fixed outcome, but something vulnerable to change depending upon the feedback they from friends, family and society as a whole.

This research used the Perception of Stigma Questionnaire (Perkins *et al.*, 2002) to examine children's perception of courtesy stigma. Items on this questionnaire were drawn from the literature on stigma (Perkins *et al.*, 2002). This method of examining courtesy stigma was in keeping with other published studies in this area, which have used the same format for assessment (Norvilitis *et al.*, 2002; Wahl and Harman, 1989)

The Perception of Stigma Questionnaire was found to have a Cronbach's alpha of 0.70 in Perkins *et al.* (2002) sample, suggesting moderate internal consistency. A slightly higher Cronbach alpha of 0.83 was observed in the current study, suggesting good internal consistency. However, establishing the validity of a scale with a small sample size is problematic and several concerns are raised with regards to items on this measure.

The Perception of Stigma Questionnaire asked the following questions:

1. How often do you do chores (e.g. going to the shops) with your mum?

2. How much do you enjoy going to places (like the shops) with your mum?

3. How much would you like to go out to other places with your mum?

4. How well do your friends know your mum?

5. How comfortable are you bringing friends over to your house?

6. How comfortable are you if your friends talk to your mum?

Children's raw data on this scale is shown below:

Figure 43: Children's raw scores on the Perception of Stigma Questionnaire

	Question 1	Question 2	Question 3	Question 4	Question 5	Question 6
Participant 1	.00	1.00	.00	1.00	1.00	1.00
Participant 2	.00	.00	.00	1.00	1.00	1.00
Participant 3	.00	.00	.00	1.00	.00	.00
Participant 4	.00	.00	.00	.00	1.00	.00
Participant 5	.00	.00	.00	.00	.00	1.00
Participant 6	1.00	1.00	.00	1.00	1.00	1.00
Participant 7	1.00	1.00	1.00	2.00	2.00	2.00
Participant 8	.00	.00	.00	1.00	.00	1.00
Participant 9	.00	.00	.00	1.00	1.00	2.00
Participant 10	.00	.00	.00	1.00	1.00	1.00
Participant 11	.00	2.00	2.00	2.00	2.00	2.00
Participant 12	.00	.00	.00	.00	.00	.00
Participant 13	.00	1.00	.00	2.00	2.00	2.00
Participant 14	.00	.00	.00	2.00	1.00	2.00
Participant 15	.00	.00	.00	1.00	.00	1.00
Participant 16	.00	1.00	1.00	.00	.00	.00
Participant 17	.00	.00	.00	1.00	.00	1.00
Participant 18	.00	.00	.00	.00	.00	.00
Participant 19	.00	1.00	1.00	1.00	1.00	2.00
Participant 20	.00	.00	.00	.00	.00	1.00
Participant 21	.00	.00	1.00	1.00	1.00	2.00
Participant 22	.00	.00	.00	1.00	.00	1.00
Participant 23	.00	1.00	.00	2.00	2.00	2.00
Participant 24	.00	.00	1.00	1.00	1.00	1.00
TOTALS	**2.00**	**9.00**	**7.00**	**23.00**	**18.00**	**27.00**

Questions 1-3 are problematic, as children consistently scored these questions the lowest. As it seems unlikely that a child would only perceive courtesy stigma amongst friends and no one else, these results may suggest the measure more effectively tapped children's perception of courtesy stigma in the context of peer relationships, rather than in public settings. It was concluded that questions 1-3 were not worded accurately enough to tap the necessary dimensions.

In order to protect against Type I errors, scores over six on the measure were therefore considered to demonstrate higher levels of perceived stigma (the scale ranged from 0-12). Analysing the data in this way ensured children who reported significant levels of perceived stigma had scored highly on one or all of the questions 4-6, as well as on, or instead of, questions 1-3. However, while this method of analysing the data was necessary to protect against Type I errors, it may also mean children's true levels of perceived stigma were higher than the 16.7% reported.

Ideally, a factor analysis would be performed on the Perception of Stigma Questionnaire, to explore the validity of items more thoroughly. This was not possible in the current study as such analysis would require over 100 data sets in order to avoid multicolinearity.

Given the issues with this measure, it can be argued that the researcher could have sought to develop a more robust tool to assess courtesy stigma. This might be approached by first carrying out qualitative research into the issue of courtesy stigma with the children of parents with learning disabilities, which could then generate themes that form the basis of items on a measure. This approach would be a move on from the Perkins *et al*. (2002) questionnaire, where questions were drawn from the literature rather than from the actual *experience* of children subject to courtesy stigma.

A process of item analysis could then follow and the psychometric properties of the test be developed, including pre-testing and test-retest procedures. To generate the high numbers of participants needed in order to create such a tool, children who experience courtesy stigma as a result of association with other stigmatised parents could be included (such as those who have a parent with mental health or drug and alcohol problems).

Unfortunately, developing such an instrument was not possible within the context of this practitioner doctorate, where the focus was to examine issues relevant for clinical intervention.

Alternatively, a qualitative interview approach could have been taken in the current study, specifically to examine courtesy stigma. A mixed methodology could have been used to interpret the data between this qualitative analysis of stigma and children's results on the standardised measures for self-esteem, attachment and social support.

Practical considerations ruled this method out in the current study. Children who took part were not easily accessible; the single researcher travelled around the country to meet with them on three separate occasions - to explain the research and gain consent to participation, carry out assessment for the absence of learning disability and then again to administer the measures for perception of stigma, self-esteem, attachment and social support. This process took eighteen months to complete. If a qualitative interview had been included in the methodology, it would have been necessary to add a fourth meeting to the assessment process. This was impractical given the time constraints and resources available for the study. The researcher also felt it was important to carry out the investigation with minimal disruption to children's lives. As it was possible to investigate courtesy stigma using the Perception of Stigma Questionnaire, which took 5 minutes to administer, it was concluded that a qualitative examination was not the most appropriate approach - given the broader research requirements. Nonetheless, a qualitative interview would have yielded a more thorough examination of the issue and future research should ideally use this methodology, particularly in the absence of a standardised measure.

Quantitative approach

This research adopted a quantitative methodology. Although this was chosen in order to examine causality between variables, it did not therefore provide in-depth exploration of children's subjective experience, with respect to perception of stigma, self-esteem, attachment or social support.

The path analysis approach used a within-groups methodology, but it would have been informative to include a control group of non-learning disabled children, matched for economic status, also vulnerable to courtesy stigma as a result of association with a parent who held a stigmatised status (such as mental health or drug and alcohol problems).

The inclusion of a control group would have enabled comparison of findings, which may have been particularly interesting with respect to children's attachment. Children in this study indicated that 'Angry Distress' on the Adolescent Attachment Questionnaire was the most significant difficulty within the attachment relationship. Whether or not this was a characteristic of learning disabled parenting could have been investigated by comparing results with a matched control group.

Measurement of resilience

This study measured children's resilience at one fixed point in time. This is in keeping with other resilience studies that have taken a similar approach (e.g. Schwartz *et al*., 2000), although, as Herrenkohl *et al*. (1994) point out, resilience at one stage of life does not guarantee later adaptive outcomes. While the current study identified attachment as a protective factor for children, the availability of the attachment relationship may be effected if, for example, a mother becomes involved in a destructive intimate relationship, which results in a child being removed into care. In such circumstances, the primary relationship will no longer be available during times of distress, which may impact upon children's resilience. A more accurate picture of the role of attachment in resilient functioning would have been achieved if the study had been carried out on several occasions over a longer time period.

This research isolated courtesy stigma as the risk to child development. Yet, the children of parents with learning disabilities usually face a number of complex entwined threats to development; as a consequence of parental learning disability and low socio-economic status (Nicholson and Cleaver, 2008). It is difficult to draw out the effects of courtesy stigma therefore, without these other factors influencing outcomes. This is a common problem in resilience investigations (e.g. Owens and Shaw, 2007) and was a limitation in the current study.

Other attachment relationships

This research did not directly examine child attachment to fathers, or to mothers' boyfriend. However, the Social Support Questionnaire (Sarason *et al*., 1987) did invite children to record up to nine supportive relationships in their life. Of the children, 72.3% reported their fathers, or their mothers' partner, as key supports.

The decision not to examine father-child attachment was taken as the majority of the literature on the parent-child relationship (within the context of learning disabilities) has focused on mothers, as has the literature on attachment more generally (Prior and Glaser, 2006). Therefore, in order to be able to view current research findings in the context of the wider literature, child attachment to mother was focused upon. Yet many fathers (or mothers' boyfriend) of low socio-economic status are unemployed and therefore may also function as a primary care-giver to children in the home. Consequently, this study may have not fully investigated the nature of children's primary attachment relationships.

Recommendations for future research

Recruitment

Future quantitative research may look to generate larger numbers of participants as, clearly, larger sample sizes promotes greater reliability and generalisability of findings. One way this might be facilitated is to draw on the support of a key professional, someone who already has a relationship with the learning disabled parents. This may help mothers feel more confident to participate in such research.

Participants could also be recruited via schools and general practitioner practices in low-income areas, rather than via health and social services. Many mothers with learning disabilities actively avoid the statutory services and only come to the attention of community teams once problems have arisen. In such circumstances they may be less inclined to participate in research. Consequently, it is likely that studies which recruit via different sources may generate larger numbers of participants.

Investigating stigma

A thorough qualitative examination of courtesy stigma from the perspective of the child is missing from the literature (Link *et al*., 2004; Perkins *et al*., 2002). Future research may consider investigating this issue generally in the children of parents of stigmatised groups (including children of parents who are HIV positive, have mental health problems or drug and alcohol addiction) and specifically in the children of parents with learning disabilities.

Further examination of the Perception of Stigma Questionnaire (Perkins *et al*., 2002) is recommended, in order that the reliability and validity of the measure be better established. More broadly, a standardised measure with strong psychometric properties should also be developed to assess courtesy stigma in children.

Investigating attachment

Out of the 20.8% of children who reported significant attachment difficulties, most did so on the Angry Distress subscale of the Adolescent Attachment Questionnaire. Research that compares attachment for children whose parents have learning disabilities, with a group matched for socio-economic status, may help clarify if this is a characteristic of learning disabled parenting.

Looking at the findings of the current research in the context of the wider literature, a potential relationship is identified between Angry Distress on the Adolescent Attachment Questionnaire and Axis II psychopathology on DSM-IV (American Psychiatric Association, 1999) (Hesse, 1999). Future studies could investigate this issue further and assess children for mental health difficulties and attachment style; in order to clarify if a causal relationship exists between Angry Distress on the Adolescent Attachment Questionnaire and psychopathology in this population.

In this research, 72.3% of children listed their father, or mothers' boyfriend, as a significant support on the Social Support Questionnaire (Sarason *et al.*, 1987). Future investigation might examine child attachment to fathers (or mother's boyfriend) in measuring resilience; which would provide a more detailed analysis of children's attachment bonds within the family.

Previous research has highlighted that the children of parents with learning disabilities are most commonly removed into care for reasons of perceived neglect by their parents (Booth *et al*., 2005). Such neglect is typically due to omission of basic child-care, rather than active abuse (McGaw and Newman, 2005). One explanation for this type of neglect might be increased rates of maternal insecure attachment style. As Howe (2005) points out, insecure maternal attachment can manifest itself in passive and unresponsive care-giving, features characteristic of neglectful parenting.

A recommendation for future research is to carry out investigation into attachment styles of mothers with learning disabilities, to establish if there is a higher prevalence of insecure attachment in this population. It is also advised to investigate the relationship between insecure maternal attachment style and child neglect, particularly in instances where neglect is considered to be as a result of omission of care rather than abusive intention.

This study identified attachment and social support as resilience factors for the children of parents with learning disabilities who were at risk of courtesy stigma. Future investigations might examine if these resilience factors can protect against other risks to development, such as poverty and maltreatment.

Investigating gender-related issues

Females in this research reported higher levels of perceived stigma than males. This was true of the younger as well as older females in the cohort. This finding was not in keeping with previous evidence, which has identified perceived discrimination tends to increase with child age (Szalacha *et al*., 2007). This discrepancy could be explained by the increased rates of attachment problems evident in the female cohort; insecure attachment is likely to negatively effect children's expectations of others (Howe, 2005), increasing the risk of self-stigma (Corrigan *et al*., 2006). Future research could seek to examine gender differences in this regard.

The current research also identified gender differences on the measures for self-esteem and social support. As with perception of stigma, these differences were explained by females' higher levels of attachment problems, which were shown to have a casual relationship with self-esteem and social support. It may also be that

females' elevated scores in this regard were attributable to adolescence (all male participants were aged 8-12 years old). Collectively, such gender differences warrant further investigation in future research.

There were significantly more females than males (62.5% female, 37.5% male) in this research. One explanation for this might be males are more likely to be monitored under child protection plans than females and, as such, would have been excluded from participation in this study. Previous empirical investigation has identified that males are more prone to externalise distress than girls, leading to higher incidences of conduct disorders (Kim and Cicchetti, 2004), as a result of which they may more easily come to the attention of services. This could therefore be a pertinent issue for the sons of parents with learning disabilities (Feldman and Walton-Allen, 1997) and requires examination in future research.

A different methodology

This research took an exclusively quantitative approach to examining perceived stigma, self-esteem, attachment and social support for the children of parents with learning disabilities. To further develop the investigation into resilience, future research might take a qualitative approach to explore these variables in greater depth; which would provide us with a better understanding of children's lived experience in this regard.

5.6 Conclusion

This small scale exploratory study took a variable-focused approach in examining resilience to courtesy stigma in the children of parents with learning disabilities. This methodology allowed for clear definitions of risk, resilience and adaptive behaviour, which have been missing in the literature to date.

Results indicated that secure child attachment to mother could act as a resilience factor, which protects children's self-esteem from the negative effects of courtesy stigma. These findings were in keeping with previous research, which has identified attachment as a resilience factor for children faced with other risks to development (Collishaw *et al.*, 2007; Kim and Cicchetti, 2004; Owens and Shaw, 2007).

Interventions designed to promote secure mother-child attachment may therefore be a focus for clinical practice. Attachment-based treatments have been shown to be effective with low-income families, where multiple risks (such as poverty and mental health problems) are present. They have also been found to bring about change in relatively short-term interventions of between five and sixteen sessions (Bakermans-Kranenburg, 2003). Accordingly, services to parents with learning disabilities could look to include such approaches in working with these families.

Supportive peer relationships have also been shown to act as a resilience factor for children faced with adversity (Bolger and Patterson, 2001a; Bolger *et al.*, 1988; Schwartz *et al.*, 2000). However, children in this research demonstrated a lack of same age relationships, instead relying on family members for support. This highlights a specific vulnerability for these children that should be a focus for clinical intervention. Furthermore, children's level of social support was found to be predicted by the degree of security in their attachment relationship: those with greater attachment-related problems reported lower levels of social support. Children with poor attachment to their primary care-giver may therefore benefit from targeted intervention to help them develop effective support networks.

In order to isolate perception of stigma and attachment for clear examination in this study, it was necessary to apply a number of exclusion criteria when recruiting participants. Research outcomes were established in a group of non-learning disabled children, whose mother was their primary carer and where there were no child protection issues. Yet, in effect, these findings provide a baseline, from which is possible to hypothesise that attachment may operate in a similar way for children who are learning disabled themselves, as well as for those who are monitored under child protection plans.

To date, research into outcomes for these children has focused more on the damage they suffer as a result of their upbringing, than factors which help them thrive despite adversity (Booth and Booth, 1997). The findings of the current investigation therefore contribute to a new focus for research and intervention; resilience in the children of parents with learning disabilities.

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SECTION D:

IS PSYCHODYNAMIC PSYCHOTHERAPY EFFECTIVE WITH ADULTS WHO HAVE LEARNING DISABILTIES?

A review of the literature

Contents

Introduction

People with learning disabilities are known to experience mental health problems at a rate at least three times higher than the general population (Borthwick-Duffy, 1994; Deb, Thomas and Bright, 2001; Iverson and Fox, 1989). Despite this they were not offered 'talking treatments' in response to mental health problems with any regularity until the 1980's (Bender, 1993).

Since then, psychologists have increasingly employed a range of models in working with this population, including the cognitive behavioural, systemic and psychodynamic approach (Hodges, 2003). A small body of literature on psychodynamic psychotherapy and learning disabilities has emerged; which is the focus of this review (e.g. Beail, 1998; 2001; Beail and Warden, 1996; Beail, Warden, Morsley and Newman 2005; Beail, Kellett, Newman and Warden, 2007; Corbett, Cottis and Morris, 1996; Frankish, 1989; Heinemann, 1999; Miller, 2004; Newman and Beail, 2005; Sinason, 1992; Symington, 1981).

The literature reports some encouraging findings, but a number of methodological flaws are evident in the study designs. There is a clear need for more robust empirical research to be undertaken; to date there have been no randomised controlled trials at all in this area (Beail, 2003).

The aim of this paper was to provide an overview of the evidence for the effectiveness of the psychodynamic model in working with the learning disabled population.

What is psychodynamic psychotherapy?

Psychodynamic psychotherapy is a key model of therapeutic intervention used by counselling psychologists, in the treatment of a range of difficulties, from depression to personality disorders.

Palmer, Dainow and Milner (1996) describe that, from the psychodynamic perspective, the human psyche is viewed as continually engaged in defensive manoeuvres, aimed to protect the conscious mind (or 'ego') from the threat of overwhelming instincts or feelings contained by the unconscious, or from potentially aggressive attacks on functioning caused by the 'superego' (the critical, moralising aspect of the psyche).

Although psychodynamic counselling has a complex theoretical base, the fundamental premise is that psychic defences designed to protect the ego generate anxiety, as well as a range of psychological, emotional and behavioural problems (Malan, 1979).

Malan (1979) describes the relationship between defences, anxiety and hidden feelings as a 'triangle of conflict':

Defence   Anxiety

Triangle of conflict

Hidden impulse or feeling
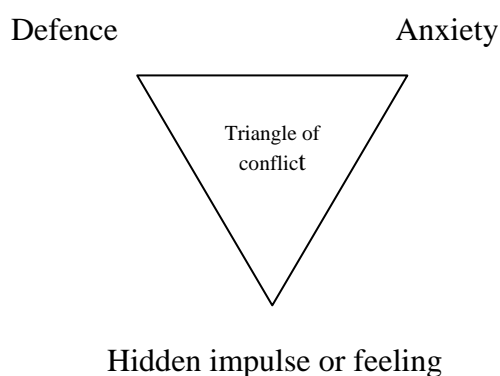
For example, a person who has experienced abuse in childhood may have limited conscious awareness of the events themselves, or their psychological and emotional impact (hidden feeling). Yet they may experience chronically low self-esteem in adulthood, leading to anxiety and behavioural 'acting out' such as self-injury (defence).

The aim of psychodynamic psychotherapy is to reach beneath psychic defences and anxieties to the true feelings and impulses (Malan, 1979).

There are a number of dynamics which facilitate this process, the most significant of which is the interaction of thoughts, feelings and projections the client brings to the relationship with their therapist (Smith, 1987).

It is assumed that a client will interact with their therapist in similar ways to previous relationships. For example, if they have a history of being abused by significant others, they may be fearful of trusting the therapeutic alliance, predicting they will be harmed in some way. This process is termed 'transference'. The client projects unbearable parts of the self and their experiences onto the therapist; who acts as a container for such feelings and impulses, giving meaning and understanding to them, transforming them into a more tolerable form. The client is then able to absorb back and 're-introject' their experience. The re-working of client projections is termed 'counter-transference' (Beail *et al*., 2007).

The process of transference and the therapeutic relationship is described by Malan (1979) as the 'triangle of the person':

<div align="center">

Other   Transference

(usually current)   (usually here-and-now)

Triangle of person

Parent

(usually distant past)

</div>
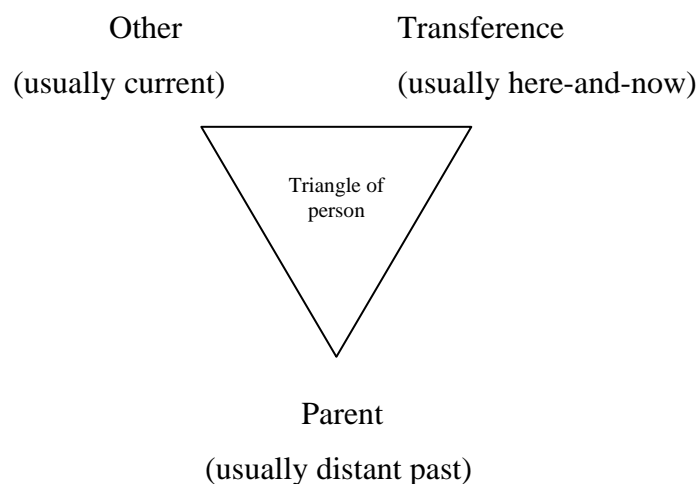
The client-therapist relationship is therefore central to this mode of therapy. It is one where trust, respect, containment and commitment are cornerstones of the interaction.

Psychodynamic psychotherapy and people with learning disabilities

As a 'talking treatment', one might think psychodynamic psychotherapy would not be appropriate for a population characterised by cognitive and language deficits. Yet, Sinason (1992) makes an important distinction between cognitive and emotional intelligence; a person may have limited intellectual understanding, but this does not mean they have compromised emotional functioning. She suggests that, although a learning disabled client may not possess sophisticated language or thinking ability, these are not pre-requisite skills for psychotherapy. Indeed, good psychotherapy is about unconscious communication, more often expressed in emotion and in the counter-transference than verbally (Sinason, 1992).

However, the literature suggests a number of adaptations may be necessary to make the model accessible to the learning disabled population.

People with severe cognitive deficits may rely heavily on the therapist interpreting non-verbal communication, and need resources such as toys and art materials to aid the work (Symington, 1981; Sinason, 1992).

Many people with learning disabilities depend on carers and/or family members in managing their day-to-day lives. This reliance might include actually bringing them to the therapy sessions. As those who support the client may not value the therapy (and in some cases may even try to sabotage it) their role can be crucial to its success. In order that they facilitate the treatment, Bungener and McCormack (1994) suggest it may be helpful to meet with carers and/or family members (with the consent of the client) at the beginning of the process, and occasionally throughout the treatment. This helps those who support a person with a learning disability to understand the importance of attending sessions regularly and on time.

Lee and Nashat (2004) draw attention to a further issue that can arise. They point out that the process of psychotherapy necessarily requires a creative 'space' between client and therapist, where thinking and reflection can take place. This can be difficult to achieve if the client is overly dependant. The lives of people with learning disabilities often contain abandonment, abuse, institutionalisation, social

stigmatisation, poor coping skills and little social support – factors which can all give rise to a dependant style of relating to others. Where this dependency manifests itself in the therapeutic relationship, it restricts the ability to reflect and the relationship becomes two dimensional, making it difficult for creative understanding to take place. Therapists may need to consider how best manage this style of relating if psychodynamic intervention is to be effective (Lee and Nashat, 2004).

Lastly, Reyes-Simpson (2004) suggests that the discrepancy in social status between therapist and client can be painful to the learning disabled individual. This often leads professionals to try and protect clients from knowledge of their difference. She argues that facing this difference is crucial however, if a client is to benefit from treatment. As such, fostering the capacity to address unpalatable truths about the impact of disability is necessary, if a climate for real development is to be achieved.

In conclusion, the literature suggests that a learning disability is not a barrier to treatment, although a number of adaptations may be required in order that interventions meet the needs of this population.

The nature of the evidence base for learning disabilities

Research has shown psychodynamic psychotherapy to be an effective intervention for a range of problems in the non-disabled population (Roth and Fonagy, 1996). However, there seems to have been little research into its use with the learning disabled.

In 1996, Roth and Fonagy published an extensive meta-analysis of the psychotherapy literature. Entitled *What Works for Whom*, this review summarised the evidence base from over 2000 references. In doing so it established psychodynamic psychotherapy as an effective treatment modality for a number of psychological and behavioural difficulties.

Yet, references to research which considered its applicability for people with learning disabilities were omitted. Beail (2003) points out this may be because, at the time, psychological treatments for people with learning disabilities comprised mostly behaviour modification or behavioural skills training. Little evidence even existed.

Beail's (2003) point is well illustrated by two meta-analyses:

The first was carried out by Scotti and colleagues in 1991. They covered four hundred and three interventions for problem behaviours in people with cognitive limitations. All involved single case studies, of which three hundred and ninety-eight used behavioural models of intervention and five used medication. Not one used any kind of 'talking treatment', such as psychodynamic or cognitive behavioural intervention.

A more recent investigation by Didden *et al.* (1997) involved analysis of one thousand four hundred studies, which had examined the effectiveness of treatments for problem behaviours in this population. Only one study reported a non-behavioural technique.

However, it should be pointed out that these two extensive reviews did overlook a small handful of case study investigations. These case studies may have been excluded wittingly, as they were published in books focused on theoretical discussion, rather than in research journals.

There are a number of factors which could explain the lack of existing literature on this subject, not least reluctance on the part of the psychoanalytic community to engage in empirical research in general (Beail *et al*., 2005). On the whole the psychodynamic field has been dominated by theoretical discussion, rather than studies investigating the effectiveness of treatment.

Indeed, many psychodynamic psychotherapists have long argued that the effects of this mode of treatment are not measurable using standardised tests (Beail *et al*., 2005). Furthermore, they argue that attempts to measure such interpersonal phenomena would damage the therapeutic alliance and hence influence the treatment effect (Beail, *et al.,* 2005). This has impacted upon research into the usefulness of psychodynamic treatments for the learning disabled (Bender, 1993).

This is exacerbated by the fact that so few psychodynamic psychotherapists work with people with learning disabilities. The psychotherapy training schemes offered by the British Confederation of Psychotherapists (BCP) and the United Kingdom Council for Psychotherapy (UKCP) do not include the needs of people with learning disabilities within their courses (Sinason, 2002).

There are a variety of possible explanations for this, some of which can trace their roots to Sigmund Freud. The psychodynamic community was, for many years, influenced by Freud's (1953) assertion that people must be well educated to benefit from this treatment approach (Bender, 1993). As a result, there have been longstanding concerns that people with learning disabilities will not understand the process of therapy, due to decreased cognitive abilities (Bender, 1993). Fortunately, this view has changed over recent years and a learning disability is no longer seen as a contra-indication for psychotherapy (Bungener and McCormack, 1994).

Even so, psychodynamic psychotherapy is a rare resource across the statutory services, and not offered within NHS learning disabilities services with any regularity (Sinason, 2002). As a treatment it is more commonly offered by private practitioners, and is therefore often beyond the financial reach of people with learning disabilities.

Combined, these factors have meant the burgeoning evidence base for psychodynamic intervention has been slow to develop (Beail, 2003).

This literature review therefore considered the small number of papers published to date, which have considered the effectiveness of psychodynamic psychotherapy for people with learning disabilities.

Method

A literature search in peer reviewed psychiatry, psychology, nursing and social care journals from 1980 to 2008 was conducted. The following sources were searched: BNI, CINAHAL, EMBASE, HEALTH BUSINESS ELITE, HMIC, MEDLINE and PsychINFO. In addition a manual search was made through relevant published books and articles.

Search strategies were conducted using variations on the following: PSYCHOTHERAPY, PSYCHOANALYTIC, PSYCHODYNAMIC, ADAPTATIONS, TREATMENT, THEMES, PROCESS, OUTCOMES, RESULTS, LEARNING DISABILTIES, INTELLECTUAL DISABILTIES, MENTAL HANDICAP and SUBNORMAL.

Papers were identified that directly addressed the question 'are psychodynamic models effective in treating psychological and behavioural problems for adults who have learning disabilities?' Papers and articles that did not address this question were excluded from this review. Only studies which had considered adult psychotherapy were included. There were no other inclusion criteria.

Results

This literature search identified a small number of quantitative studies (Beail, 1998; Beail, 2001; Beail and Warden, 1996; Beail *et al.*, 2005; Beail *at al.* 2007; Beail and Newman, 2005) and two case studies which had been published in peer review journals (Frankish, 1989; Symington, 1981).

A number of books were identified, which report the application of the model with this population. Written or edited by pioneers such as Corbett *et al.* (1996), De Groef and Heinemann (1999), Sinason (1992) and Simpson and Miller (2004), these books largely focused on theoretical discussion of the psychodynamic model, although several authors detailed their discussion with case studies. Relevant individual chapters from these books have been included in this review.

In total, twelve studies were identified, which presented original data on the effectiveness of the psychodynamic model to treat psychological, emotional and behavioural difficulties for people with learning disabilities. These studies are discussed below.

Table 1: **Studies presenting original data on the effectiveness of the psychodynamic model to treat psychological and behavioural problems for people with learning disabilities**

Author	N	Type of study	Presenting problem	Methodology and results
Beail (1998)	25	Pre-post evaluation using behavioural measures.	Behaviour problems leading to offending behaviour.	Weekly individual psychotherapy. Gains maintained at 6 month follow up.
Beail (2001)	18	Comparison between treatment group (n = 13) and refusal to treatment group (n=5).	Criminal offending behaviour.	Weekly individual psychotherapy. Of the 13 who received treatment, 11 had not re-offended after 4 years. All 5 of the men who refused treatment re-offended.
Beail and Warden (1996)	10	Pre-post treatment Evaluation using measures of self-esteem and psychological symptoms.	A range of psychiatric symptoms.	Weekly individual psychotherapy. Results indicated improvements in self-esteem and reduction in psychiatric symptoms.
Beail *et al.* (2005)	20	Naturalistic evaluation: pre-post treatment using measures for psychiatric and interpersonal symptoms.	Aggressive behaviour (n=9) sexually inappropriate behaviour (n=3), psychotic behaviour (n=3), relationship problems (n=1), self-injury (n=1), depression (n=1), bulimia (n=1) and OCD (n=1).	Weekly individual psychotherapy. Significant reductions were seen in recipient's levels of psychological distress and interpersonal problems. Self-esteem increased.
Beail *et al.* (2007)	20	Within group design, comparing the outcomes for clients who received 8 sessions, 16 sessions and 24 sessions respectively. The aim was to establish the no. of psychodynamic sessions necessary to bring about change for learning disabled adults.	Aggressive behaviour (n=9) sexually inappropriate behaviour (n=3), psychotic behaviour (n=3), relationship problems (n=1), self-injury (n=1), depression (n=1), bulimia (n=1) and OCD (n=1).	Weekly psychotherapy, administered in 8, 16 or 24 sessions. This study concluded that most change appears to happen in the first 8 sessions.
Corbett *et al.* (1996)	3	Case studies.	Sexual abuse trauma.	Weekly individual psychotherapy. Authors report clients' ability to process severe emotional trauma.
Frankish (1989)	7	Case studies.	OCD, aggression and challenging behaviour.	Weekly or bi-weekly psychotherapy. Author reports clients emotional development.

Heinemann (1999)	1	Case study.	Behavioural problems and bereavement for an autistic man.	Weekly psychotherapy. Author reports a reduction in ritualised behaviours and increases in day-to-day living skills.
Miller (2004)	3	Case studies.	Social anxiety and depression.	Weekly individual psychotherapy. Author reports decreases in negative superego functioning and developments in ego strength.
Newman and Beail (2005)	8	Pre-post comparison of functioning, using retrospective analysis of case notes.	Anxiety related problems (n=4), behaviour problems (n=3), and sexual offending behaviour (n=1).	Weekly individual psychotherapy. Authors report that clients demonstrated the ability to assimilate their problematic experiences through the therapeutic process.
Sinason (1992)	2	Case studies.	Self-injury, sexually inappropriate behaviour.	Weekly individual psychotherapy. Improvements in self-injurious behaviour in the first case study. No outcomes given for the second case study.
Symington (1981)	1	Case study.	Challenging behaviour.	Weekly individual psychotherapy. Significant developments in personal autonomy and intellectual functioning.

Quantitative studies

In total six quantitative studies were identified (Beail and Warden, 1996; Beail, 2001; Beail, 1998; Beail *et al*., 2005; Newman and Beail, 2005; Beail, 2007). These are not without methodological weaknesses, not least a lack of definition of learning disability and limited numbers of research participants. However, they do provide some preliminary insight into the number of sessions necessary to bring about change, and the rate at which assimilation takes place during treatment. There is also suggestion the model may be useful in treating a number of psychiatric symptoms, improving self-esteem and reducing the rate of recidivism in offenders.

Number of sessions needed to bring about change

Beail *et al*. (2007) conducted a study with twenty clients to examine the amount of therapy required to produce positive results (the 'dose-effect'). The authors explain that the number of sessions at which change is seen to occur in the general population is between 8 and 10 (Hansen *et al*., 2002). Consequently, Beail *et al*. (2007) aimed to establish the dose effect in the learning disabled population. In total, 3 women and 17

men participated in the study, all of whom had mild learning disabilities. The reasons for referral were; aggressive behaviour (n = 9), sexually inappropriate behaviour (n = 3), psychotic/bizarre behaviour (n = 3) and also one person each with relationship difficulties, self-injury, depression, bulimia and obsessive-compulsive disorder respectively. Progress was measured using the SCL-90R, which measures symptom areas including somatisation, obsessive compulsive disorder, phobic anxiety, depression and paranoid ideation (Derogatis, 1983). The Inventory of Interpersonal Problems (Horowitz *et al.,* 1988) and the Rosenberg Self-esteem Scale (Rosenberg, 1965) were also used to assess outcomes.

Treatment consisted of the client free associating (discussing and exploring material they considered important), and the therapist making interpretations in the transference, helping to reach beneath anxieties and defences to hidden feelings. The authors explain that a further facet of the therapy was to provide a reparative parental relationship, particularly where the client's original parenting was deficient, abusive or over-protective.

In order to examine the dose-effect, eight participants underwent an 8 session treatment, five received a 16 session intervention and eight a 24 session intervention. The authors found most change occurred in the first eight sessions of treatment, and consequently conclude the dose-effect for psychodynamic psychotherapy for people with learning disabilities is similar to that in the general population.

While they provide a helpful guide as to the amount of therapy needed to bring about change, Beail *et al.* (2007) unfortunately do not discuss the relationship between cognitive ability and dose-effect. Severe learning disability is not considered to be a barrier for treatment (Sinason, 1992), nonetheless, people with milder disabilities might require fewer sessions - the ability to effectively communicate their difficulties influencing the amount of sessions needed. Inclusion of such information would have been informative.

Developing insight into difficulties

In a similar paper, Beail and Newman (2005) investigated the rate at which eight clients with mild learning disabilities developed insight into their difficulties over the course of treatment. This was investigated using the Assimilation of Problematic Experiences Scale, which was applied to process transcripts for sessions 1, 4 and 8. Results showed clients increased awareness into their problems, within and across 8 sessions.

This study provided an interesting account of the stages during therapy, where a client demonstrated psychological change. Yet, as with Beail *et al.'s* (2007) paper, there was no discussion on how cognitive function may relate to the process of assimilation. Additionally, the Assimilation of Problematic Experiences scale provides no norms by which these participants' outcomes could be compared. This, combined with the small number of participants, means there is limited applicability of these findings to the rest of the population.

Reduction in psychiatric symptoms and improving self-esteem

Two studies considered psychodynamic psychotherapy as a treatment for a range of psychiatric symptoms and problem behaviours.

Beail and Warden (1996) conducted a study into intervention effectiveness with 9 men and 1 woman, referred for aggressive behaviour (n = 4), sexually inappropriate behaviour (n = 3) and psychotic/bizarre behaviour (n = 3). Participants received between 5 and 48 treatment sessions, the mean was 18. The pre-post outcome measures used were the SCL-90R and the Rosenberg Self-esteem Scale. Intervention focused on using the transference and counter-transference to understand the internal world of the client.

Results showed participants increased in self-esteem and decreased in symptoms on the SCL-90R as a result of treatment.

Again investigating symptom reduction, Beail *et al.* (2005) looked at the effectiveness of intervention with 17 men and 3 women, aged between seventeen and forty-eight years old. Of the participants, 9 were referred due to aggressive behaviour, 3 because

of sexually inappropriate behaviour and 3 due to psychotic behaviour. The remaining 5 referrals were due to relationship problems, self-injury, depression, bulimia and obsessive compulsive disorder respectively. Clients were given weekly psychodynamic psychotherapy. The number of sessions ranged from 5 to 48, with a mean of 13.2. The authors explain that, using Malan's (1979) triangle of conflict, treatment consisted of using the transference and counter-transference to help clients make sense of their feelings and impulses.

Outcomes were assessed using the Rosenberg Self-esteem Scale, the SCL-90R and the Inventory of Interpersonal Problems measures. As a result of treatment, psychiatric symptoms reduced and self-esteem increased for all participants.

Both of the above studies reported positive treatment effects but, again, no information was given as to the participants' level of learning disability. The sample sizes were small (n = 10 and n = 20 respectively), not randomly selected and no control groups were used; all factors which reduce the ability to generalise the findings to the rest of the population. Also, the SCL-90R, Inventory of Interpersonal Problems and the Rosenberg Self-esteem Scale were used as pre/post treatment measures, but it is not clear if these measures always tapped progress with respect to the clients presenting problem. Bulimia, for example, is not assessed by any of these scales, which raises issues of validity with respect to some of the findings.

Reduction in offending behaviour

Two studies considered the effectiveness of the model for people who had, or were at risk of, committing a criminal offence.

Beail (2001) reported an intervention with eighteen learning disabled men. All the participants had been arrested for an offence and diverted from the criminal justice system to a psychotherapy service for adults with learning disabilities. In total, 13 men consented to treatment and 5 were discharged. Of those who took part in treatment, 11 were referred for sexual offenses, 1 for theft and 1 for arson. Their ages ranged from seventeen to forty-two years old. Participants received weekly psychodynamic psychotherapy; the treatment length ranged from 4 to 43 months.

Intervention consisted of free association; interpretations were made using Malan's (1979) triangle of conflict.

None of the men reoffended while in treatment and 11 had not reoffended 4 years after treatment was completed. Of the 5 who refused intervention, 3 reoffended within 12 months, one within 2 years and one within 4 years. Consequently, Beail (2001) concluded that psychodynamic psychotherapy was effective in reducing the rate of recidivism for men with learning disabilities.

It appears that, while there was no matched control group in this study, outcomes compared positively against those who refused treatment. Yet it may be those who refused intervention had more complex problems, leading to higher rates of offending, which would have been maintained regardless of treatment. Also, there were no pre/post outcome measures, other than the rate of recidivism. As offending behaviour may be influenced by many factors, it is not clear that the treatment itself was the actual cause of the reduction in behaviour.

Another study by Beail (1998) investigated psychodynamic treatment for 20 men, 12 of whom were referred due to aggression and 8 because they had committed a criminal offense. These men were consecutively referred to a service for psychodynamic psychotherapy, over a three year period.

Participants received weekly psychodynamic psychotherapy; treatment length varied from 3 to 38 months. During treatment, clients' discourse was considered within the contexts of transference and Klein's (1948) developmental theory. Clients were encouraged to free associate and the therapist provided interpretations based on Malan's (1979) triangle of conflict.

The effectiveness of the intervention was measured in two ways. First, with respect to behaviour problems, carers and family members recorded the frequency of the target behaviour in the participant before, during and after treatment, and at six months follow-up. Second, treatment of offending behaviour was evaluated by assessing the index offence and then parents and carers recorded whether there had been any further incidents during the course of treatment, and at six-month follow-up. The treatment

was considered to be successful in most cases; the problem behaviour was eliminated and this was maintained at follow-up.

Although treatment outcomes were positive, a weakness in this study was its lack of matched control group. As the sample size was small (n = 20), it is therefore difficult to conclude that treatment effects accounted for the elimination in behaviour, rather than the passage of time. Also, the method of assessing outcome itself may have reduced the participants' likelihood of engaging in the target behaviour, as they were aware of being monitored closely by carers and family.

Qualitative case studies

The case study reports by Corbett *et al*. (1996), Frankish (1989), Heinemann (1999), Miller (2004), Sinason (1992) and Symington (1981) naturally allow for more detailed analysis with regards to client case formulation than the pre/post treatment enquiries. As such they provide a helpful insight into the model and how it may be used, although the nature of case studies does not allow for generalisation of findings. Nonetheless, it seems psychodynamic psychotherapy may be effective in helping people to develop emotionally; as well as aiding psychological maturity. It has been used in the treatment of self-injury, sexual abuse and coping with bereavement.

Facilitating emotional development

Frankish (1989) reported a psychodynamic intervention with seven clients referred to a psychology service. Clients presenting problems were not specified. The author explains that the decision to use a psychodynamic approach was based on the preference of the therapist and the similarities in behaviour between clients and the children described by Mahler *et al.* (1975). They were offered weekly or bi-weekly sessions; length of treatment varied between nine months and two and a half years.

Intervention drew on Mahler *et al.'s* (1975) theory, which described distinct consecutive stages of early development, the achievement of each one necessary in order to reach psychological maturity. Frankish (1989) suggests many adults with learning disabilities have deficits in cognitive or emotional function as they have been

unable to successfully negotiate one of these stages of development. Consequently, treatment focused on helping clients address difficulties which had caused them to remain fixed at a certain stage. Frankish (1989) concluded that intervention based on the work of Mahler *et al*. (1975) can help facilitate developments in emotional maturity.

There are some weaknesses in the paper, however. Little information is given on exactly how Mahler *et al.'s* (1975) stages of development were used to guide the process of intervention. Level of learning disability was not described, or how this may or may not have related to clients presenting problems, nor treatment outcomes. Consequently, the degree to which interventions were successful is difficult to ascertain.

Symington (1981) reports a case study of a young man named Harry, whose IQ was 59 (mild learning disability range). Harry was referred for psychotherapy because of his aggressive behaviour in a day centre. He was seen by the author for weekly treatment, over a two year period. Symington (1981) drew on the theories of a number of psychoanalytic practitioners, including Bergson (1919), Mannoni (1972) and Segal (1957) to inform the work. The process of sessions, and key themes that emerged, are discussed within the context of these theories.

One such theme was the relationship between Harry and his mother. At the beginning of therapy, Symington (1981) observed how his client was unable to differentiate himself from his parent. Harry functioned in a 'state of primary identification' that would be expected of a child in the first stages of life. Symington (1981) explained that this ego identification between mother and child is not unique, as it is also seen in the psychopathic, psychotic and borderline personality disorder patient. However, in learning disabled clients, it has a bearing on intellectual capacity. Intelligence itself presents a threat as it signifies separation from mother, which there is a strong pull against (Symington, 1981).

Lack of separation from parents not only effects intelligence, but leaves the learning disabled individual vulnerable to a damaged sense of self (Symington, 1981). During pregnancy any mother will hope for the arrival of a perfect child. When a learning

disabled child is born, she is confronted with trauma and disappointment at the loss of the 'normal' baby. The handicapped child then exists within this maternal perception, absorbing the reflected knowledge of their imperfection. As a consequence, a sense of disappointment is often internalised; a belief they are fundamentally inadequate. This knowledge can generate a type of secondary handicap, more debilitating than the original organic deficit itself, which has a negative effect on emotional development (Symington, 1981).

Symington (1981) describes how psychotherapy fostered an emotional separation between Harry and his mother; in order that his sense of personal value was not so heavily determined by her perception. As that separation occurred, his cognitive abilities also improved. By the end of therapy, he had gained a greater sense of autonomy and was able to assert himself far more. He chose not to attend his day centre any longer, and was able to conduct a conversation that 'would have been quite impossible before the therapy began' (Symington, 1981, p. 195). The author concludes that 'my intuition is that psychotherapy can partly or wholly restore the intellectual faculty' for people with learning disabilities (Symington, 1981, p.198)

Symington's (1981) paper provides insight into the process of psychotherapy with a learning disabled client. He makes clear and informative links between the material generated in sessions and psychodynamic theory. Writing at a time when such literature was limited, this paper was one of the first of its kind. His interesting suggestion that psychotherapy may be able to restore cognitive function is one which would be helpful to investigate via empirical research.

Ego development

In a case study of three clients, Miller (2004) describes how intervention helped facilitate ego growth for people with learning disabilities. The first client described in Miller's (2004) paper was referred due to her level of social withdrawal. This lady was reported to have a mild learning disability. The second client had Down's syndrome, and was referred due to depression. No reason was given for the referral of the third client, nor was level of learning disability reported. Miller (2004) provides a summary of the work with these three clients, using Bion's (1962a) theory to illustrate the case material.

The main theme addressed was the negative influence of the clients' 'punitive superego', which caused them to take a harsh and judgemental approach to themselves. Miller (2004) suggests this punitive superego arises as a consequence of primary disappointment at having a learning disability. In keeping with Symington (1981), Miller (2004) explains how the learning disabled child internalises their mothers' negative perceptions of their existence, as a consequence of not being the 'perfect baby'. She suggests this leads to the development of a punitive superego, which then exerts a dominating influence over the development of the individual; impeding the ability to grow cognitively.

Miller (2004) explains how, during the process of therapy, this punitive authority figure was projected onto the therapist, in the transference. Through sensitive use of counter-transference, the therapist was able to help the client to recognise their self-criticism; increasing their sense of personal value and strengthening their ego. Thus, the harsh superego was gradually modified by the therapeutic relationship.

Miller's (2004) case studies are informative, but she does not explain how learning disability was assessed, nor detail the reason for referral with one of the clients. No information was provided with regards to the number of sessions given. Furthermore, the psychodynamic structure of the psyche (superego, ego and unconscious) is an abstract concept and changes in how it operates are difficult to measure. Although improvements in superego functioning were witnessed by Miller (2004) during the process of the therapy, how these may have then manifested themselves in terms of the clients' actual day-to-day functioning were not discussed.

Treatment for self-injury
Sinason (1992) reports a case study with Maureen, a severely handicapped woman with no verbal language, who was referred for severe self-harming behaviours, including head banging, eye-poking and self-biting. Maureen was offered weekly psychodynamic psychotherapy, and was seen for 100 sessions in total.

Sinason (1992) provides a summary of the sessions, drawing out key relevant themes. She points out how people with severe learning disabilities may express their emotional, psychological and physical distress through a myriad of behaviours,

including self-harm. Carers and family involved in the lives of such people can too easily blind themselves to the ways in which distress is communicated, often erroneously attributing self-harming behaviour the original disability. However, no organic deficit itself leads directly to self-injury; it is a symptom of an individual's distress (Sinason, 1992).

In fact, Sinason (1992) suggests that people who care for the severely learning disabled may have much invested in remaining ignorant to these behaviours – their meaning being too painful. She argues such behaviour must be examined carefully during the process of therapy, in order to understand it; to grasp whether it is suicidal, depressed, in response to physical or emotional pain, or an infantile way of dealing with feelings.

Due to Maureen's low cognitive functioning, toys, pictures and art materials were used to facilitate communication; although simple verbal interpretations were still made. During the process of therapy, her behaviours were explored and began to be understood; as a result of which she developed increased vocal noises and physical movements. Self-harm significantly decreased. Sinason (1992) concludes that intervention promoted ego development for Maureen, which reduced her need to express distress through self-harm.

Sinason's (1992) work suggests that psychodynamic intervention could be used successfully with someone who has severe learning disabilities. Interestingly, it reports that the client was able to respond to simple verbal interpretations from the therapist, despite having no verbal ability herself; although a substantial number of sessions were required to facilitate change.

In a second case study, Sinason (1992) details a psychodynamic intervention with a young man called Howard, who was referred due to head banging, masturbating in public and furious attacks on staff who were not 'giving him a woman'. Howard was described as physically disabled and had cerebral palsy.

In her work with Howard, Sinason (1992) draws out themes from the sessions and observes how the process of development through the psycho-sexual stages can be

impaired for the mentally handicapped. She points out that many adults with cognitive and physical deficits are unable to take responsibility for their personal care, which leaves them dependant on parents or carers to perform intimate tasks. Sinason (1992) suggests this often means help is needed with toileting and bathing, which places handicapped adults in a vulnerable and confusing position. Sexuality is necessarily repressed, leaving the individual in an infantile role, despite an adult body. She argues that such complications mean the learning disabled person may therefore remain fixed at early stages of sexual development. Immature defence mechanisms are maintained, blocking the potential for sexual maturity.

Sinason (1992, p.273) argues that the learning disabled often have to face a 'basic narcissistic disappointment' about their desirability to others. As she describes, every adolescent is aware of a 'hierarchy of selection that is caused by levels of attractiveness' (Sinason, 1992, p.273). She suggests that the learning disabled person needs to face their position on that hierarchy, which in itself presents a painful challenge that may generate self-hatred.

To illustrate this, Sinason (1992, p.271) reports Howard's dialogue from a session, where he described how he did not want a girlfriend with a disability such as his own: 'I don't want the ugly ones. That's all I get. The ugly ones no one wants. The ones in wheelchairs, the ones with no proper faces. The ones that can't speak'.

Intervention focused on helping Howard to face his handicap and its impact upon his sexuality. However, he was reluctant to do so, which Sinason (1992) described as a kind of self-sabotage, one which ultimately prevented him from forming an intimate relationship.

This case study highlights how psychodynamic intervention can be used to address the complex issues that can arise for someone with a learning disability, with regards to their own sexuality and that of others. However, no information was provided on the level of Howard's learning disability, or what adaptations in technique might have been necessary to facilitate the therapy. No detail was given on the number of sessions he was seen for. Lastly, no information was given as to the impact of the intervention on Howard's self-injurious or sexually inappropriate behaviour.

Treatment for sexual abuse

Corbett *et al.* (1996) report on an intervention with three clients who had been referred to a psychotherapy service as a result of sexual abuse. They discuss the process of therapy and consider how their clients' learning disabilities presented an additional trauma.

The first client, Tim, had been recruited into a paedophile ring at the age of 8 years old. He later worked as a prostitute and developed a significant substance misuse problem. At the time he came to therapy he was homeless. Tim was given weekly psychodynamic psychotherapy and, over the course of time, was able to process the abuse he had suffered. However, Corbett *et al.* (1996) describe how, even once the horrors of his maltreatment had been faced, Tim was still left with the difficult task of coming to terms with his learning disability. The authors report he stopped attending his psychotherapy abruptly, although by that point had already noted a significant improvement in his functioning. He had found permanent accommodation, stopped using drugs and had also begun attending a day service for young people.

The second client, Jenny, was referred by her social worker, and had suffered sexual abuse at the hands of her father. Jenny had been reporting abuse to those around her, including her mother, for many years, but had been told she was 'mad'. Her social worker had believed her story and facilitated the referral. Corbett *et al.* (1996) describe the importance of communicating to Jenny that she was being listened to and her experiences believed. For the first 26 sessions, Jenny disclosed the nature and duration of the sexual abuse. This led to police involvement, despite which her father was not prosecuted. However, Jenny was able to move to a safe home, away from the family and the abuse.

The third client, Helen, was referred due to ritual abuse by a satanic coven. She presented for treatment in a dissociated state, engaging in repetitive self-injury, having made several suicide attempts and was drinking alcohol heavily.

Helen disclosed the abuse she had suffered over the course of the sessions and demonstrated an unusual coping mechanism. Her defence against painful memories

was to dissociate into a projection of how she wished she could be; she often shifted to a state where she spoke lucidly from the perspective of a no-nonsense Irish woman.

Corbett *et al*. (1996) point out that in non-disabled clients, regression normally involves returning to an earlier developmental state. Yet, for Helen, regression back to an infantile state meant facing the trauma of being born learning disabled. Dissociating into a projection of how she wished herself to be therefore provided more refuge from her abuse trauma than primary regression could offer. No treatment outcomes were reported for Helen, as the therapy was ongoing at the time Corbett *et al*. (1996) wrote their paper.

These three case studies by Corbett *et al*. (1996) describe how psychodynamic psychotherapy could be used with people who have learning disabilities, who have been subject to severe sexual abuse. They also highlight how the trauma of learning disability often underlies other traumas. Yet, as with previous case studies reviewed, there is a lack of background information given; such as level of learning disability, the length of treatment, or any adaptations made to the model.

Treatment for bereavement

Heinemann (1999) reported a case study of a man with autism, 'Mr R', who he saw for weekly therapy over the course of two years. Mr R was referred as he was finding it difficult to cope with the death of his father, leading to an increase in ritualised behaviours. He was only able to walk down streets in one direction and he had become disruptive at home.

Heinemann (1999) drew out themes from the sessions which were discussed in the context of psychodynamic theories of Mahler (1975) and Tustin (1983). From these theoretical standpoints, autism is understood as either a fixation or a regression to the first stage of extra uterine life. At this stage the mother is unrecognised and no distinction can be made between animate and inanimate objects. Knowledge of the outer world and inner world are denied by defence mechanisms and there is a sustained retreat into an internal world, which is directed by the senses.

In this state of isolation, people's behaviour becomes idiosyncratic and ritualised. Information from senses is separated and isolated, so there is a fundamental breakdown in communication internally as well as with the outside world. This leaves the autistic adult with a sense that the world is unpredictable and chaotic, generating intolerable anxiety. Rigid patterns of thinking act as defences against such fear (Heineman, 1999).

Heinemann (1999) demonstrated how psychodynamic treatment helped Mr R integrate information from his senses, reducing pervasive feelings of anxiety about the loss of his father. Interestingly, the author describes how, during the process of therapy, he was required to function as an 'auxiliary ego' to Mr R, to help him make sense of experiences and provide a bridge to the external world. In doing so, Mr R was given a pathway for his own ego to develop.

By the end of treatment, Mr R's anxiety reduced and he was able to give up most of his rituals; allowing himself to walk down streets in both directions. His ability to communicate with people around him improved, and he was able to engage more fully with the concept of his father's death.

Heinemann (1999) reported some alterations in technique with this client. He observed how Mr R required him to continually ask questions in order to stimulate ego function and that too much silence within the therapy sessions could generate anxiety. He concluded that whilst the usual dynamic techniques of transference, counter-transference and interpretation remain the same, the therapist must take a much more active role than would be usual in this form of therapy.

This informative case study demonstrates how the model can be effectively used to help an adult in difficult emotional circumstances. Heinemann (1999) details information from the sessions with Mahler (1975) and Tustin's (1983) psychoanalytic theories, helping the reader to understand how they informed the work. He also highlights adaptations which were necessary to facilitate the therapy. However, he does not describe the level of Mr R's cognitive ability. Someone with autism will not necessarily have a low IQ. As higher levels of intellectual functioning may influence

the ability of the individual to understand the process of therapy, information about Mr R's level of cognitive ability would have been useful.

Discussion and conclusion

Psychodynamic psychotherapy has been shown as effective for a number of mental health difficulties in the non-disabled population (Roth and Fonagy, 1996). Yet, despite a growing interest in the use of psychotherapeutic methods with the learning disabled, there has been little research published in this area (Willner, 2005). This literature review identified twelve studies in total (Beail, 1998; 2001; Beail and Warden, 1996; Beail *et al*., 2005; Beail *et al.,* 2007; Corbett *et al*., 1996; Frankish, 1989; Heinemann, 1999; Miller, 2004; Newman and Beail, 2005; Sinason, 1992; Symington, 1981) which reported treatment effectiveness.

Learning disability is not seen as a contra-indication for psychodynamic therapy (Bungener and McCormack, 1994). Even those with severe disabilities have been found to benefit from treatment, as emotional intelligence is not necessarily determined by cognitive ability (Sinason 1992). The lack of research is therefore not attributable to clients' limitations. Rather, it may be because psychodynamic psychotherapy is a scarce resource within NHS learning disabilities services (Sinason, 2002), an issue compounded by the fact it is difficult for researchers to evaluate treatment outcomes using standardised measures (Beail *et al.*, 2005). An overarching complication is the lack of tradition of empirical investigation within the psychodynamic community itself (Beail *et al*., 2005). Collectively, these factors may have restricted the growth of the evidence base.

The model may be suitable for this population, but the wider literature suggests adaptations in style and technique are sometimes necessary (Lee and Nashat, 2004; Reyes-Simpson, 2004; Sinason, 1992). For example, using art materials and toys to facilitate communication (Sinason, 1992), or including family members and carers in the treatment process, in order that they support the therapy (Bungener and McCormack, 1994). Yet, with the exception of Sinason (1992) and Heinemann (1999) such adaptations are not mentioned in any of the studies reviewed.

'Psychodynamic' is an umbrella term for a number of theories. Malan's (1979) 'triangle of conflict' and 'triangle of the person' are concepts relevant to all

psychodynamic conceptualisations, but there are important distinctions in terms of emphasis between, for example, the developmental stages of Mahler *et al.* (1975) and the theories of Klein (1948). Some of the authors in this review, including Beail (1998), Frankish (1989), Heinemann (1999), Miller (2004) and Symington (1981), explained the theoretical base from which their interventions were drawn. These included Bergson (1919), Bion (1962a), Klein (1948), Mahler *et al.* (1975), Mannoni (1972), Segal (1957) and Tustin (1983). However, many of the studies reviewed did not (Beail and Warden, 1996; Beail, 2001; Beail *et al.*, 2005; Beail *et al.*, 2007; Corbett, Cottis and Morris, 1996; Newman and Beail, 2005; Sinason, 1992). Given the differing emphases of the psychodynamic theories, it would seem important for future studies to provide more detailed information in this regard, so that the focus of the formulations and interventions are clear.

A number of methodological weaknesses were evident across the studies reviewed, which made it difficult to ascertain treatment effectiveness.

Quantitative investigations relied on small sample sizes, ranging from n = 10 (Beail and Warden, 1996) to n = 20 (Beail, 1998). No matched control groups were used and participants were not randomly selected. Furthermore, the six studies by Professor Nigel Beail (Beail, 1998; Beail, 2001; Beail and Warden, 1996; Beail *et al.*, 2005; Beail *et al.*, 2007; Newman and Beail, 2005) drew their participants from a service for people with learning disabilities, from one geographical area in England. Collectively, these weaknesses in design mean clients may not have been representative of their population and as such findings have limited generalisability.

Several of the quantitative studies evaluated treatment outcomes using measures which did not necessarily assess change on the client's original presenting problem (Beail and Warden, 1996; Beail *et al.*, 2005; Newman and Beail, 2005; Beail *et al.*, 2007). Participants were therefore reported as having increased in self-esteem (Rosenberg, 1965) and decreased in symptoms measured on the SCL-90R (Derogatis, 1983) or the Inventory of Interpersonal Problems (Horowitz *et al.*, 1988), despite the fact they were, in several instances, referred for issues not measured by the above scales. Consequently claims of treatment effectiveness have questionable reliability with respect to a number of the studies. However, it should be noted that there are

few norm referenced standardised scales to measure therapeutic change in this population; an issue well established in the literature (Willner, 2005). It may therefore be that the measures cited above were considered a 'best fit' in terms of the assessment tools available to the researchers.

None of the quantitative studies provided any detail of how clients' learning disabilities were established – whether that was on the basis of professional opinion, or using standardised assessments. Similarly, with the exception of Symington (1981), the case studies do not provide specific information about the level of learning disability. As such, it is not clear that all of the reported interventions were carried out with adults who met the criteria for learning disability as defined by DSM-IV (American Psychiatric Association, 1999). Some may have been of borderline or low average IQ range, which could influence the process of treatment; those with higher IQ's potentially having more effective verbal communication. The relationship between verbal functioning and therapy outcomes may therefore be noteworthy, but is not addressed by any of the studies reviewed.

This point is particularly pertinent to the investigations by Newman and Beail (2005) and Beail *et al.* (2007), which investigated the dose-effect necessary to bring about change, and the rate at which assimilation takes place in therapy. While they described their clients as 'mildly learning disabled', they do not say whether or not verbal ability had any influence over either the dose-effect or the process of assimilation; information which would have been helpful.

Several of the case studies described interventions lasting a number of years (Frankish, 1989; Heinemann, 1999; Sinason, 1992; Symington. 1981). It seems plausible that the amount of therapy required to bring about change may vary - not only in relation to a client's level of verbal ability, but with respect to the nature and severity of their psychopathology. However, some studies, such as Frankish (1989) and Miller (2004), did not provide information on the client's presenting problem, so it is difficult to glean the extent to which their difficulties influenced the length of treatment.

Where the need for long-term therapy is indicated, there are significant cost implications to services. This level of intervention might therefore be beyond the financial reach of the statutory learning disabilities services - if the aim were to provide it on a nationwide basis (Sinason, 2002). This may mean that psychodynamic psychotherapy remains the focus of a small number of specialist services, such as Professor Beails', reducing the rate at which the evidence base will grow.

In many respects, the case studies by Symington (1981) and Miller (2004) illustrate some of the reasons why the psychodynamic community has tended to take a theoretical case study, rather than quantitative, approach to research. Symington (1981) addressed his client's need for emotional separation from his mother, as a path to greater ego and cognitive development. Similarly Miller (2004) reported how psychodynamic psychotherapy was effective in modifying clients' punitive superego, to promote ego growth. Concepts such as the ego and superego are core to the psychodynamic model, but the changes in functioning described by these authors are difficult to quantify using standardised assessments.

The case studies by Symington (1981), Miller (2004) and Corbett *et al*. (1996) provide an interesting exploration of the impact on the psyche of having a learning disability. Symington (1981) and Miller (2004) suggest that maternal disappointment at not having the 'perfect baby' is internalised by the child. They argue this gives rise to defences which prevent the learning disabled individual from separating emotionally or psychologically from their mother; the effects of which are more handicapping than the original disability. Another defence against the trauma of disability was noted by Corbett *et al*. (1996), in their work with Helen. They suggest it led to her atypical style of disassociation; to a projection of how she wished she could be rather than to an earlier regressive state. Again, while these are informative theoretical observations, such concepts are difficult to quantify outside of the psychodynamic case formulation.

Despite these methodological flaws, taken in the round the evidence to date provides a positive indicator for treatment effectiveness. It seems psychodynamic psychotherapy might help promote emotional development (Frankish, 1989; Symington, 1981) and facilitate ego growth (Miller, 2004). It may also improve self-esteem and reduce

symptoms such as somatisation, obsessive compulsive disorder, phobic anxiety, depression and paranoid ideation (Beail and Warden, 1996; Beail *et al.,* 2005). Case studies have illustrated its effectiveness in the treatment of self-harm, coping with the effects of sexual abuse and the process of bereavement (Sinason, 1992; Corbett *et al*., 1996; Heinemann, 1999). There is some evidence to suggest that it can also be effective with men at risk of offending behaviour (Beail, 2001; 1998).

The UK National Health Service Executive (NHS Executive, 1996) supports the use of this type of research to guide clinical practice in the absence of randomised control trails, but there is clearly a substantial requirement for further studies in this area, if this treatment modality is to develop a stronger evidence base.

Psychodynamic psychotherapy is not alone in this respect however; there is limited evidence with regards to 'talking treatments' in general with this population (Willner, 2005). This includes research into the effectiveness of the cognitive behavioural and cognitive models - the most dominant of the psychological treatments in adult mental health services (Willner, 2005).

Yet, irrespective of the quantity of research, it would appear that Freud's (1953) assertion is at best questionable; people with learning disabilities are suitable clients for psychodynamic psychotherapy. The evidence base is slowly developing and the signs are that it will continue to do so.

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