A Portfolio of Study, Practice and Research Work:

Submitted for the
Doctorate of Psychology (PsychD) in Clinical Psychology

University of Surrey

"Exploring the Experiences of Fathers of Young Children with Autistic Spectrum Disorders: A Qualitative Study"

Volume 1

Andy Gentil

2002
Acknowledgements:

I thank sincerely the following people who helped me throughout the three years of clinical training.

Thanks to my clinical placement supervisors; Leo Estall, Siobhan Woollett, Rosemary Armstrong, Lynne Benjamin, Catherine Dooley, Sarah Helps, Sue Bodger and Maria Callias.

Thanks to all those professionals from other disciplines whose input to my clinical placements has been crucial.

Thanks to Catherine Carraretto and Brian Solts for their advice and help in their roles as Clinical Tutors.

Thanks to Mick Finlay, Maxine Tostevin and Sarah Lovekin for their help with my Major Research Project.

Thanks also to my trainee colleagues, friends, family and my wife Jackie.
Copyright Statement:

No part of this portfolio may be reproduced in any form without the written permission of the author, except by the University of Surrey Librarian for legitimate academic purposes.

© Andy Gentil, 2002
Contents:

Introduction to the Portfolio 1

Academic Dossier Frontpage 2

Academic Dossier Overview 3

Adult Mental Health Essay 4
"Compare and contrast the effectiveness of CBT and systemic therapies in the treatment of eating disorders".

People with Learning Disabilities Essay 22
"Services for older people with learning disabilities require a fundamentally different philosophy than those for younger people with learning disabilities. Critically evaluate the arguments for and against this statement".

Child and Family Essay 45
"Critically evaluate psychological theories of child abuse and their contribution to clinical practice".

Older Adults Essay 65
"The ageing process gives rise to many inevitable psychological and physical changes. Discuss".

Specialist Child and Family Essay 85
"To what extent is the cognitive-behavioural approach to pain and its management relevant to children undergoing painful medical procedures?".
Summaries of Case Reports Completed during Training

Adult Mental Health Case Report Summary
“The outpatient treatment of a thirty year old man presenting with obsessive compulsive disorder”.

People with Learning Disabilities Case Report Summary
“The cognitive assessment of a client with a mild learning disability and bipolar affective disorder”.

Child and Family Case Report Summary
“An assessment and short psychodynamic intervention with a nine year old boy referred for behaviour and emotional problems”.

Older Adults Case Report Summary
“A narrative intervention with a seventy-eight year old gentleman who presented with depression”.

Specialist Child and Family Case Report Summary
“The cognitive assessment of a ten year old boy with sickle cell disease”.

Summaries of Placements and Clinical Experience

Core Adult Mental Health Placement Summary

Core People with Learning Disabilities Placement Summary

Core Child and Family Placement Summary

Core Older Adults Placement Summary

Specialist Child and Family Placement 1 Summary

Specialist Child and Family Placement 2 Summary
<table>
<thead>
<tr>
<th>Contents</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Research Dossier Frontpage</strong></td>
<td>132</td>
</tr>
<tr>
<td>Research Dossier Overview</td>
<td>133</td>
</tr>
<tr>
<td><strong>Service Related Research Project</strong></td>
<td>134</td>
</tr>
<tr>
<td>&quot;Clients' Views on Psychologists, Outpatient Psychology Services and Therapy&quot;.</td>
<td></td>
</tr>
<tr>
<td>Abstract</td>
<td>135</td>
</tr>
<tr>
<td>Introduction</td>
<td>136</td>
</tr>
<tr>
<td>Results and Analysis</td>
<td>138</td>
</tr>
<tr>
<td>Discussion</td>
<td>146</td>
</tr>
<tr>
<td>References</td>
<td>150</td>
</tr>
<tr>
<td>Appendices</td>
<td>151</td>
</tr>
<tr>
<td><strong>Literature Review</strong></td>
<td>159</td>
</tr>
<tr>
<td>&quot;A review of research literature related to stress and coping in fathers of children with autism&quot;.</td>
<td></td>
</tr>
<tr>
<td>Introduction</td>
<td>160</td>
</tr>
<tr>
<td>Summary and Conclusions</td>
<td>175</td>
</tr>
<tr>
<td>References</td>
<td>179</td>
</tr>
<tr>
<td>Appendix</td>
<td>183</td>
</tr>
<tr>
<td><strong>Major Research Project</strong></td>
<td>184</td>
</tr>
<tr>
<td>&quot;Exploring the experiences of fathers of young children with autistic spectrum disorders; a qualitative study&quot;.</td>
<td></td>
</tr>
<tr>
<td>Contents</td>
<td>185</td>
</tr>
<tr>
<td>Abstract</td>
<td>186</td>
</tr>
<tr>
<td>Introduction</td>
<td>187</td>
</tr>
<tr>
<td>Method and Procedure</td>
<td>200</td>
</tr>
<tr>
<td>Results and Analysis</td>
<td>207</td>
</tr>
<tr>
<td>Discussion</td>
<td>232</td>
</tr>
<tr>
<td>References</td>
<td>243</td>
</tr>
<tr>
<td>Appendices</td>
<td>249</td>
</tr>
</tbody>
</table>
Introduction to the Portfolio:

The Portfolio contains a selection of work completed during the author’s PsychD in Clinical Psychology training at the University of Surrey.

The Portfolio aims to highlight the range of experience obtained during the PsychD course and aims to reflect the variety of clinical, academic and research competencies developed over three years of training.

Volume I

This volume comprises;
The Academic Dossier which contains five essays.
The Clinical Dossier which contains summaries of the five clinical case reports and summaries of the six clinical placements undertaken.
The Research Dossier which contains the service related research project, qualitative research project, literature review and major research project.
Within each dossier, work is ordered chronologically.

Volume II

This volume comprises;
The five clinical case reports.
Summaries of further clinical work undertaken on each of the six placements, including placement contracts, logbooks and evaluation forms.
Due to the confidential nature of the material, this volume of the Portfolio will be held within the Psychology Department at the University of Surrey.
Academic Dossier
Academic Dossier:

This section of the portfolio contains four essays completed during each of the four core placements and one essay based on an issue relating to the first specialist placement.

The essays critically evaluate psychological theory and practice across a variety of issues and across a range of client groups.
Adult Mental Health Essay

Compare and Contrast the Effectiveness of CBT and Systemic Therapy in the Treatment of Eating Disorders.

December 1999
Year 1
Compare and Contrast the Effectiveness of CBT and Systemic Therapies in the Treatment of Eating Disorders.

Introduction:
This essay sets out to address the question by reviewing significant studies which aimed to assess the effectiveness of the alternative therapies and by considering wider issues of measurement and outcome as applied to the treatment of eating disorders. The essay does not give extensive details of methods used in different therapies as this does not address the question directly and there is wide variety between studies.

This essay will address the treatment of anorexia nervosa and bulimia nervosa. There are discrepancies in the availability of literature on the disorders, with most studies addressing the treatment of bulimia followed by anorexia (Hawton, Salkovskis, Kirk & Clark, 1989). The essay does not deal with treatments for Binge Eating Disorder (BED) as at the present time even the prevalence of this disorder is not known (Krause, 1999). Diagnostic criteria have changed over the time-course of the literature reviewed here, with most studies using the criteria of DSM-III-R. However, as many of the studies comprise follow-ups of previously treated samples, and the changes in diagnostic criteria not being fundamental, this issue should not be critical.

For a short description of the disorders and their prevalence see Roth and Fonagy (1996). The high comorbidity of eating disorders with other psychiatric disorders (personality disorder, obsessive-compulsive disorder and depression) should be noted, as the effectiveness of any treatment for eating disorders may be impacted upon by the effectiveness of the treatments on these comorbid conditions also, if not fully controlled for within clinical trials.

The mortality rate in anorexia has been expressed as a 600% increase over that of the normal population and may be higher in bulimia (Patton, 1988). Hospitalisation will be indicated for less than 5% of cases of bulimia (Hawton et al., 1989). Crisp (1991) has shown that in anorexia a comprehensive inpatient treatment package can demonstrate clear clinical gains post-therapy, but that there is a significantly higher rate of relapse after one year compared to outpatient treatments.
Therefore there is a drive toward providing effective psychological outpatient treatments for those suffering from eating disorders due to the high mortality rate, the distressing and chronic nature of many cases, the lack of evidence to support pharmacological treatments and the lack of evidence for the long-term effectiveness of inpatient care programs.

Most of the studies discussed here are aimed at defining the effectiveness of outpatient treatments for eating disorders in producing remission, clinically significant improvement and avoiding re-admission to hospital. There is a bias toward studying severe cases as they are the client group likely to be contact with services in sufficient numbers at the point of admission to secondary / tertiary services.

The interest in cognitive behavioural treatments for eating disorders is based on models proposed for the maintenance of other disorders such as depression (Beck, Rush, Shaw & Emery, 1979) and the effectiveness of some behavioural in-patient interventions. The eating disorder can thus be explained as being maintained by negative thoughts, beliefs about weight, shape and eating behaviour and schema.

The interest in Systemic therapies for eating disorders stems largely from work at the Philadelphia Child Guidance Clinic (Minuchin, Rosman & Baker, 1978) where a model was proposed in which anorexia frequently became apparent in a specific type of "psychosomatic family". The term Systemic Therapy covers a number of disparate models, however most of the research cited in this essay assess the effectiveness of Family Therapy. This has been the only systemic therapy who's effectiveness has been studied using controlled methodologies on this patient population. A number of recent studies have used the specific form designed at the Maudsley hospital (Dare & Eisler in Garner & Garfunkel, 1997).

Causality should not be concluded from either of these models, and neither seem sufficient to explain the range of presentations and variables involved in eating disorders, but they have served as the rationale for the construction and testing of therapeutic interventions, and also serve as the rationale for this essay.
Research into the Treatment of Anorexia Nervosa

Effectiveness of CBT in Anorexia:
Channon, Hemsley and Perkins (1989) compared CBT, behaviour therapy and a control condition of routine outpatient management for 24 female anorexic patients (from the Maudsley Hospital eating disorders service). There were significant flaws in the design and completion of the study. The sample size was small and both treatment and assessment were completed by the same researcher. But the findings are often quoted despite this, as it was one of the first attempts at a controlled trial of treatment for anorexia.

The study measured patients’ B.M.I. (Body Mass Index), scores on the Morgan and Russell Scales (1975), the E.D.I. (Garner, Olmsted & Polivy, 1983), B.D.I. (Beck, 1978) and M.O.C.I. (Hodgson & Rachman, 1977) and patients’ preferred weight. At post-treatment the researchers found that none of the groups differed significantly on any of the measures although all groups showed some improvement over pre-treatment (in weight, menstrual and nutritional functioning). At 1 year follow up, with the treatment conditions combined, they differed from the control condition on social functioning only. The researchers also found that compliance was higher in the CBT than the Behavioural condition. This is important as anorexic patients are often difficult to engage in treatment.

The study as a whole can be taken as evidence that this particular cognitive behavioural treatment carried out by the named practitioner was no more effective than a behavioural one and neither are significantly superior to the crudely defined outpatient management condition.

The use of CBT in the treatment of anorexia is still evident, and although outcome studies are remarkably absent, therapists continue to extend and refine treatment techniques. Vitousek claims that the basis of collaborative empiricism inherent in CBT is a useful factor in the engagement of clients in therapy especially when we consider the egosyntonic nature of the illness and the strengths of beliefs held (Krause, 1999).
Recent interest in the concept of Thought-Shape Fusion (Shafran, Teachman, Kerry & Rachman, 1999) and its occurrence in eating disorders would also be an avenue of evidence to suggest that CBT may be a useful treatment strategy, one of it’s methods of action being that of addressing cognitive distortions. The authors link this to work on obsessive compulsive disorder using the similar concept of thought-action fusion, where CBT interventions are used as the treatment of choice.

**Effectiveness of Systemic Therapies in Anorexia:**

One of the most often cited studies in this area is by Russell, Szmukler, Dare and Eisler (1987). The study aimed to contrast family therapy with individual supportive therapy. The study’s sample consisted of mostly anorexic patients (N=57) with a subgroup of people with bulimia (N=23), all of whom had received inpatient treatment to regain weight. Measures grouped into good, intermediate and poor outcomes (using average body weight and menstrual function) and also weight showed that subjects under the age of 18yrs whose illness was of short duration (< 3yrs) responded better to family therapy, whereas subjects over 18yrs with longer duration responded better to individual therapy (though not as strong a finding).

Following from these encouraging findings for family therapy with a subgroup of anorexic clients, a study examined the method of action involved. The authors compared supportive therapy (offered to the patient and family in separate sessions) and conjoint family therapy (the traditional model where all members attend the same session). The sample was of 18 patients and there were no significant differences between the groups at the 1 year follow up. This was followed by a further study of 40 patients which again showed both forms of therapy enabled patients to regain and maintain weight in outpatient treatment (Le Grange, Eisler, Dare & Russell, 1992).

Eisler, Dare, Russell, Szmukler, Le Grange and Dodge (1997) have produced a 5 year follow-up study of the large patient sample (N=80) used in their previous studies at the Maudsley Hospital. This confirmed the findings from the earlier study (Russell et al. 1987) which were that family therapy is more beneficial to anorexic clients whose illness onset is before the age of 18 years and whose duration is less than three years.
This result holds across scores on the Morgan-Russell scales, weight gain and the outcome categories that were defined in the previous study. The second finding was that individual therapy is more beneficial for clients with late onset anorexia. Patients whose illness was of longer duration than 3 years and had onset before 18 years of age had a poorer prognosis than those in the other groups regardless of treatment condition.

I feel there is a tendency to overstate the findings of this study however, as the improvements did not reach statistical significance for the late onset group (N=14) in weight and general outcome, so the conclusion is mostly based on mental state and psychosexual adjustment within the Morgan-Russell scales. The family therapy group advantage in the early onset (short history) group is based on the mean outcome rating and the menstrual function subscale. The between group advantage in average body weight found at one year follow-up has not been found at five years. Thus the reliability, validity and discriminative power of the instrument used is crucial in drawing strong conclusions, see Morgan and Russell (1975).

Hall and Crisp (1987) looked at the effectiveness of a psychodynamic family therapy compared to that of an individual intervention. The study found no differences between treatment conditions on the global ratings, but found a family therapy advantage on measures of sexual and social adjustment. This study, though not claiming to use a systemic model to underpin therapy, might be said to lend weight to the case for intervening in the family milieu as well as on an individual level.
Research into the Treatment of Bulimia Nervosa

Effectiveness of CBT in Bulimia:
The lack of controlled trials measuring the relative effectiveness of treatments for eating disorders in the mid to late eighties prompted some researchers to group the many case-study series available to form meta-analyses. One such study grouped together a number of uncontrolled trials often with very small sample sizes (N<5). The author found post-treatment effect sizes of .60 for pharmacological therapies and 1.30 for psychological treatment including dietary management (Laessle, 1987 cited in Roth & Fonagy, 1996).

A later analysis by Hartmann, Herzog & Drinkman (1992 cited in Roth & Fonagy, 1996) used only studies with N>5, and again used bingeing / purging as outcome measures (the only commonly measured variables across the studies) and also included control group data. The authors found that psychological treatment (mainly CBT) had a post-treatment effect size of 1.04. This increased for treatments over 15 sessions, and reduced for treatments less than 13 sessions in length. These results lend support to the hypothesis that psychological (primarily CBT) therapies can be effective in treatment of bulimia when compared to the effect size for control groups of 0.18 which is a measure of spontaneous remission or illness course over the short term.

Wilson and Fairburn (1993) reviewed studies published between 1989 and 1992 of CBT for patients with bulimia. Their data shows that for the four studies included in the sample, CBT led to very similar significant reductions in both bingeing and purging (approx. 70-90% reduction). Patients rated as being in remission was as in other studies, somewhat lower.

Mitchell, Pyle, Eckert, Hatsukami, Pomeroy and Zammerman (1990) which was included in the Wilson and Fairburn review (1993), included pharmacological treatment and placebo groups. Binge eating reduction was (9% for the placebo condition, 34% for the imipramine group compared to CBT and CBT with imipramine conditions where binge eating was reduced by 83-92%.
Pyle, Mitchell, Eckert and Hatsukami (1990 cited in Roth & Fonagy, 1996) measured relapse rates for participants who responded to the treatment conditions of the Mitchell et al. study (1990). Relapse was most likely in placebo (83%) and pharmacological only treatment (67%). Relapse in CBT groups was 22% and 31%.

Agras, Rossiter, Arnow, Telch, Raeburn, Bruce and Koran (1994) followed up a second study included in the above review, finding that CBT alone and CBT in addition to pharmacological treatment were superior to pharmacological treatment alone for the reduction of binge eating and purging behaviours up to 1 year after treatment.

Fairburn, Norman, Welch, O'Connor, Doll and Peveler (1995) was another follow up study of a paper included in Wilson and Fairburn’s review (1993). The 1995 study found remission rates of 14% for those treated with behaviour therapy, 63% in the CBT condition and 72% in the Interpersonal Therapy condition. This and the 1991 trial show the effectiveness of CBT over behaviour therapy with this population but also show that the newly designed IPT seems to show at least as powerful an effect as CBT over a period of a year or more post-treatment. Further research is being conducted by the authors into the effectiveness of IPT following these finding.

Another issue in the evaluation of CBT treatment is the relative effectiveness of providing CBT within a group setting or an individual one. This has major implications for cost effectiveness. Wilfley, Agras, Telch, Rossiter, Schneider, Golomb, Sifford and Raeburn (1993) found that both individual and group delivery of CBT significantly reduced binge-eating compared to a waiting list control group in non-purging bulimia patients over a one year follow up period. A cognitive behavioural intervention can also take the form of self help or guided self help for example using a manual such as Schmidt and Treasure (1997).

The Cochrane Review of Psychotherapy for Bulimia Nervosa (Hay & Bacaltchuck, 1999) selecting 18 studies from the literature states that there is a significant advantage of CBT over waiting list controls when measured by level of binge eating, but that it has not been established that CBT is better than other psychotherapies, which also
show an advantage over wait lists, on this same variable. The authors also note that many of the studies have been non-blind in design and with small sample sizes.

**Effectiveness of Systemic Therapies in Bulimia:**

Results from the bulimia group within the study by Eisler, Dare et al. (1997) show that 50% have a “poor outcome” (as defined above) at 5 year follow up. This is a marked contrast to findings for the treatment of anorexic clients using the same treatment modality within that study.

It might be argued that the evidence of the effectiveness of IPT in Fairburn et al. (1995) could hinge on the interpersonal nature of the therapy and therefore give indirect evidence to support the further investigation of family therapy in the treatment of bulimia. Family variables have been explored in relation to anorexia (Minuchin, Rosmin & Baker 1978) and in the transmission of dietary restriction from mothers to non eating disordered children (Hill & Franklin 1998). The second study found that mothers of dieting girls showed differences in their own eating history, perceived their daughters to be less attractive, and were dissatisfied with aspects of family functioning in comparison to mothers of non-dieting girls (including ‘bulimia’ subscale of the E.D.I.). These finding parallel those of Pike and Rodin (1991) where mothers of eating disordered girls aged 16, were found to show higher levels of disordered eating, and show differences on the same family context variables. Offering treatment in the family context might therefore be justified on the basis of these findings. Further controlled trials are urgently required.

**Further Developments in Bulimia:**

With evidence established for the effectiveness of CBT interventions in bulimia, some recent research has gone one step further. Fahy and Russell (1993) was one such study looking at prognostic indicators in this client group’s response to CBT. Indicators were found to be pre-treatment severity, duration of illness and personality disorder at 1 year follow up.

Blouin et al. (1994) conducted a large study (N=69) to identify short term prognostic indicators for bulimic patients undergoing CBT group treatment. A number of
commonly used scale including the EDI were used. This study found that only family environment was predictive of reductions in binge frequency. Baell and Wertheim (1992) found that self-esteem, ineffectiveness and binge frequency, but not duration of illness were predictive of response on binge frequency.

Franko (1997) ran a study with 16 bulimic patients who were given a 12 week CBT group therapy intervention. The study was set up to establish whether patients who had a positive outcome (in binge frequency at post-treatment) differed from those with a negative outcome on the variable “readiness for change” (measured with the Change Assessment Scale). This was found to be the case. Thus there is evidence that similar assessments at pre-treatment might be a tool to assign patients to appropriate treatment at the appropriate time and hence increase service effectiveness.

The results of these studies together indicate that future studies into the effectiveness of treatments for this client group should attempt to control for cognitive, social, symptom variables, comorbidity and possibly duration of illness when assigning patients to treatment conditions where possible.

**Difficulties in Measuring Effectiveness in Eating Disorders:**

Clients in contact with eating disorders services vary markedly with the symptoms, frequency, severity, onset and duration of their illness (Hsu, 1990). There is an awareness that the prognostic indicators in eating disorders are not yet fully understood and therefore the heterogeneity within different client samples may be responsible for a large proportion of the variance in outcomes found between similar studies. The long time course and low spontaneous remission rates found in eating disorders also need to be taken into consideration, and a suitable follow up period used. This is especially evident following long term follow up studies such as that of the Maudsley group (Eisler et al., 1997) which show change between treatment conditions extending to years post treatment.

The theoretical underpinnings of CBT and Systemic therapies are very different and there is bound to be some difference between the two schools of thought about what constitutes effectiveness of treatment, and what we should be measuring to assess it.
Recent studies have found some middle ground by using a wide set of measures. These include measures specific to eating disorders (EDI, Morgan and Russell Scales), general measures of psychopathology (often based on cognitive theory, e.g. B.D.I.), objective measurements of weight and body mass (linked to medical prognosis). It would be worth considering however, whether the measurements taken reflect the multi-factorial aetiology and development of these complex disorders. Measures of interpersonal adjustment, beliefs, mental state and social role functioning, might be argued to be at least as important as precise measurements of weight or body mass. These issues have been included only as subscales of instruments such as the (Russell and Morgan Scales). It could be argued that this approach is not giving enough weight to these issues when measuring outcome in disorders that are generally agreed as having a complex multi-factorial aetiology and maintenance.

The common use of instruments such as the B.D.I. which are strongly based within cognitive theory could also be said likely to produce bias in outcome studies. The discriminative power to measure variables critical in cognitive models of psychopathology is not mirrored in the depth of measures of variables underpinning systemic models. This may mean that change is more likely to be found significant on variables underpinning cognitive models of eating disorders rather than those (less well defined) variables that underpin and would mark change from a systemic perspective.

Meta-analyses of the literature are hindered as they are limited to using gross measurements (such as Body Mass Index), as the use of other more specific measures and scales is not well standardised across the literature as yet. This is improving with the wider use of instruments such as the E.D.I. and Russell and Morgan scales which attempt to reflect change with a wider focus, including the interpersonal domain. Controlling for the prognostic indicators that have been established in the literature has not been done systematically across all the studies that are reported here. Authors use random allocation to address the issue, but have often been unable to provide adequate sample sizes.

Ethical issues add to the difficulties when studying treatment of eating disorders. The use of waiting list or no treatment controls is often untenable and this limits the
methodologies available to test effectiveness in these disorders. The use of self report questionnaires can also be criticised in follow up studies due to the prevalence of denial and the egosyntonic nature of anorexia. Follow up studies have thus had to use more complex and costly follow up procedures (Eisler et al., 1997).

Due to the number of clients available, the heterogeneity within the client groups and systematic bias across the service settings, it is important to bear the wider context of effectiveness studies in mind when assessing the literature. The majority of recent studies comparing the treatment of eating disorders are based within the context of medical management within the National Health Service. The increased focus on evidenced based practice will spur on further efforts to define effective treatments for those suffering from eating disorders.

**Summary of Effectiveness in Treating Anorexia Nervosa:**

CBT has not been proven to be any more effective than behavioural or general outpatient treatment for anorexia nervosa. CBT and behavioural treatments have shown gains in patients’ social functioning after a one year follow up. (Channon et al., 1989). Drop out rates in CBT were lower than with behavioural treatment. Recent work on Though-Shape Fusion may yield some further interest in using CBT for anorexic clients.

Weight and general outcome were found to respond to the Maudsley Group’s family therapy in anorexic clients under 18 years of age and with shorter illness duration. Older clients benefited more from individual psychotherapy. Many of these findings hold over five years post-treatment although the strength of the findings based on a small number of subscales from a wide range of measured variables are of limited power and some disappear at 5 year follow up (Eisler, Dare et al., 1997).

Both conjoint family therapy and separated supportive family therapy have been shown to be equally effective (Le Grange et al., 1992). Other research points to the family milieu as being a useful and appropriate place to intervene in the maintenance of anorexia using a psychodynamic model (Hall & Crisp 1987).
The case for using systemic therapy in the treatment of anorexia is backed by evidence for the use of specific forms of family therapy. The use of CBT in anorexia is not proven, though the role of cognitive variables in the maintenance of the condition continue to make it a worthy area of study. Further studies are required into CBT in anorexia and in the comparison of pharmacological and psychological interventions.

**Summary of Effectiveness in Treating Bulimia Nervosa:**

Meta-analyses point to the effectiveness of CBT over no treatment, placebo and pharmacological treatments for bulimia nervosa especially for the frequency of bingeing and purging behaviour (Mitchell et al., 1990) and also for lowered relapse rates (Pyle et al., 1990).

The effectiveness of CBT in relation to other therapies is under question after IPT was found to produce similar improvements over a year post-treatment. CBT has been shown to be more effective than behaviour therapy. Both group and individual CBT treatments have some evidence to support them (Wilfley et al., 1993).

Results for a subgroup of patients studied in the Maudsley series show that family therapy is no more effective than individual psychotherapy for bulimia nervosa. The group under study were severe cases with histories suggestive of comorbid psychopathology. The lack of studies in this particular area means that no strong conclusion can be drawn. Studies focusing on a slightly different group may yield less damning results. Comparative studies of treatments against waiting list controls would give stronger evidence. Thus there is some limited evidence that a family milieu may be a suitable place to intervene, possibly using a systemic model, as is the case in anorexia nervosa.

**Summary and Conclusions:**

There are a number of comparisons that can be made to contrast the effectiveness of cognitive behavioural and systemic interventions. Some of these can not or have not been done due to the particular difficulties explored in the previous sections.
The Cochrane review of Psychotherapy for bulimia nervosa notes a trend to publish only positive results. Though this is not unique to the field of eating disorders, the limited number of studies which have found positive results for different treatments might indicate the difficulties encountered in achieving significant change for people with eating disorders in general, or be an expression of the difficulties in measuring such change.

Further studies are needed to measure the effectiveness of psychological therapies in the treatment of eating disorders. This extends to the need to define sub-groups of patients likely to respond to different therapies, as well as testing the methods of action of new and existing therapies.

The rise of evidence based practice within the National Health Service means that tertiary eating disorder services are under pressure to provide evidence for their particular treatments. I feel that the evidence base for both cognitive behavioural and systemic therapies are questionable at present, though psychological treatments are leading the way in the management of such disorders at the present time.
References:


---

Adult Mental Health Essay


People with Learning Disabilities Essay

Services for older people with learning disabilities require a fundamentally different philosophy than those for younger people with learning disabilities.

Critically evaluate the arguments for and against this statement.

June 2000

Year 1
Services for older people with learning disabilities require a fundamentally different philosophy than those for younger people with learning disabilities. Critically evaluate the arguments for and against this statement.

Introduction:
Services for people with learning disabilities in European and North American countries have been moving through a period of substantial change over the past fifty years. There have been several major changes to the ways in which services are provided and the philosophies which underpin them. This, along with the changing demographics of the learning disabled population means that the issues discussed in this essay are of interest within the current service provision and political context in Britain.

A Growing Problem:
There are reported to be roughly 3.7 to 5.9 people with a learning disability per 1000 within the general population (in contact with services), and 3 to 4 per 1000 with a severe disability (Emerson, Hatton, Bromley & Caine, 1998). People with learning disabilities are thought to make up slightly less than 3% of the overall population of the United Kingdom. In 1996 there was estimated to be a shortfall of approximately 27,000 residential places within services (The Mental Health Foundation Committee of Inquiry, subsequently MHFCI, 1996).

The disproportionately large cohort of people born in the “baby boom” years are also now approaching the time in their life when they are likely to experience more physical and medical problems which in turn may lead to increased service needs.

The life expectancy of people with learning disabilities (especially certain subgroups, such as people with Down Syndrome) has increased substantially over the last thirty years partly due to increases in the effectiveness of healthcare services for this population (Jancar, 1988). Emerson et al. (1998) write "In common with other European and North American countries, the life expectancy of people with intellectual disabilities is increasing dramatically, although the life expectancy of
People with Learning Disabilities Essay

"people with intellectual disabilities is still lower than that of the general population" citing Strauss and Eymann (1996).

Parents themselves are ageing. One recent study found that roughly 40 per cent of people with learning disabilities living at home had one or more carer aged 60 or over. More problematically, roughly 10 per cent were looked after by a sole carer aged over 70. This represents a considerable hidden demand for housing provision, as people will need to find new arrangements when their parents die or become no longer able to cope. (The MHFCI, 1996).

These changes together mean that over the next ten years services to older adults with learning disabilities will require extensive upgrading if they are to cope effectively with the predicted increasing demand.

The nature of the services which will best meet this demand, and ways to implement them need to be considered. This essay looks at this wider issue using the statement in the title as its origin. The author will deal with the philosophies underlying provision of “services” in general terms. These include medical, psychological, day care, residential, respite, work, education and leisure service provision. This level of definition seems appropriate to deal with the issue of fundamental differences in service philosophy.

What do we Need to Consider?:
The question posed by the title, in the author’s opinion logically hinges on whether it can be proven that older adults with learning disabilities comprise a sufficiently different group with regard to their needs, preferences and behaviour from younger adults with learning disabilities. If this can be proven then there may be a case for providing services with a very different philosophy, providing we have some rationale for believing that the style of younger adult services would be harmful, or at-least not ideal for older adults.

If not, and we believe that our current services for younger adults are approximating to the best that can be achieved at present, then basing older adult services on a different
People with Learning Disabilities Essay

philosophy will be a value driven argument derived from the cultural beliefs of wider society.

On a contextual level, Walker (1996) states that "Stereotyping on the basis of age or disability is as unacceptable as doing so on the basis of race or gender." It must be borne in mind that beliefs about older adults (whether they have a learning disability or not) have often been shown to be negative in our culture (Walker et al., 1995). Therefore, we must be certain that our service philosophy does not simply express lower expectations and negative beliefs about older adults. We must also be open to the possibility that services for older adults without learning disabilities, may be far from ideal in many cases (Woods, 1996), and therefore not wisely to be held as a basis or model for services for older adults with learning disabilities.

In the case where it can be proven that older adults comprise a very different group, then we should go on to consider how service provision needs to be different, and whether this requires a "fundamental" shift in philosophy, or a more subtle alteration, or application only to a sub-group of clients who require a specialist service.

Reference will be made to medical, government, and general older adult literature, as well as that from the learning disabilities field itself as there has been little written specifically to address this question as yet. It is worthy of note that in several renown older adult texts, the issue of ageing in people with learning disabilities is dealt with in just a few sentences. Where philosophies of care are discussed, alternatives are scarce. It appears that arguments about service philosophy tend to the level of political campaigning.

The discussions found in recent learning disability journals tend to centre on the atypical and early expression of dementia in people with learning disabilities, which is relevant to this essay, though only in regards to a subgroup of older people with learning disabilities. We should not over generalise from the dementia prevalence findings within subgroups to the point where we do a disservice to the rest of the learning disabled older adult population.
Philosophies of Care, and the Ecological Approach:

In order to proceed, it is necessary to introduce two major philosophies which have a bearing on the current debate. The first derives from the work of Wolfensberger (1980), and is known as the principle of Normalization or later, Social Role Valorization. This model for services holds that society places certain groups (in this case, people with learning disabilities) in a devalued position within it. The goal of services is thus seen as to empower people to live valued lives within society.

The second theme is of Quality of Life. This is most often associated with the recent move toward requiring output data from care services, where it is seen as a possible measure. However Malin (1999) citing Goode (1988) writes about Quality of Life in a wider sense, that of being a driving principle behind care services. "The entire concept of service provision has to be redefined around individual needs and with Quality of Life as a service outcome".

There is a possible tension between these two philosophies in some instances. Especially around the care of severely disabled people and / or those with dementia where it could be argued that for practical reasons quality of life could be enhanced by a service setting which is not in line with the principle of normalization (such as a hospital based unit with considerable staff-client social distance).

A recurrent theme throughout the current older adult literature and this essay, is the ecological perspective which derives from the work of Bronfenbrenner (1979). Cantor and Little (1985) proposed a nested ecology model in which the elderly person, their close relationships, the care provision, and the wider context of society interacted. Changes in one nested ecology thus having effects across the others (see Fig 1). The approach also considers the role of changes in these nested ecologies over time, which is particularly useful for this essay, set as it is, against a background of radical service changes which the current cohort of older adults with learning disabilities have lived through.
Fig 1:

The Nested Ecology Model (over time).

Normalization and Quality of Life:
As mentioned previously, one of the major philosophies underlying current service provision is that of normalization or social role valorization (Brown & Smith, 1992). One of the major examples of this trend toward providing valued roles within the community, and one which is often quoted as being a major catalyst for change was the “All Wales Strategy” (Welsh Office, 1983).

In summarising the move to community care, starting from normalisation and incorporating wider ethical values Malin (1999) writes “The ideal has become clearer: it is for the equal acceptance and valuing of people in competent, caring, mutually beneficial communities, based on respect for the personal identity and aspirations of people while acknowledging their vulnerability.” This statement of philosophy therefore encompasses the needs of individuals with varied levels of disabilities, people whose behaviour challenges services and the author was unable to find any reason to make a distinction for older adults.
Malin (1999) summarised the aims of the White Paper, “Caring for People: Community care in the next decade and beyond” (Department of Health, 1989) saying that “The Changes outlined in the White Paper were intended to: .....enable people to live as normal a life as possible in their own homes or in a homely environment in the local community; .....provide the right amount of care and support to help people achieve maximum possible independence and, by acquiring or re-acquiring basic living skills, people would be helped to achieve their full potential; .....give people a greater individual say in how they live their lives and the services they need to help them do so. In a similar way, this statement of specific areas which should be taken into account in service design, span the writings of many authors in both the learning disability and general older adult literature.

Recommendations from the MHFCI (1996) with regard to the fundamental operation of care management for people with learning disabilities are summarised by this quotation “All care managers should offer people with learning disabilities a range of options and tailor the provision they receive to their particular needs and circumstances”. The question which naturally follows from this statement is, what range of options should we present? Do the major points of controversy such as the use of generic or specialist services, and the choice of where to live fall within this? Are we obliged to offer either generic or specialist services and allow clients to choose, or is this a choice we cannot afford in our philosophy?

Quality of Life is a topic which appears quite often in general older adult literature. Quality of Care environments have been studied by authors such as Kitwood and Bredin (1992), especially in the application to older adults with dementia, who are considered to be more at the mercy of their immediate social and care environment than those with a higher level of functioning. The author considers their work to be very applicable to people with severe learning disability, and those with both a learning disability and dementia. The major determinants of quality of life being shared, such as respect, privacy, dignity, and care delivered in an individualised manner.

Cantor and Little (1985) hold that the maintenance over time of a client’s quality of life, as the major objective of older adult services. The two literatures of older adult
and learning disabilities, come together at this point in prescriptions for the important
determinants of this elusive concept 'quality of life', on more basic level than those
noted in the previous paragraph. Some of these factors bear marked similarity to those
found in normalisation literature, such as; meaningful relationships, meaningful social
roles, adequate financial support, adequate healthcare, political and cultural
involvement and the protection of dignity and individuality.

These principles are surely of just as much importance in the care of older adults as
younger adults. Although the services provided in order to achieve them may have to
be different in structure, their philosophical basis could well be the same.

**Differences between Older and Younger Adult Services in Reality:**

Janicki and MacEachron (1984) in a paper primarily concerned with relative service
costs and written from a distinctly medical perspective, found that between 50% and
60% of elderly developmentally disabled people were living in institutional settings, as
compared to 24%-45% of the client group in younger age groups. Their data also
support earlier findings, that 30%-40% of those older adults with learning disabilities
in institutional care, did not require such a restrictive environment. These figures
suggest that the reality of services at that time in the United States, was that there were
significant differences in the provision to older adults within this client group, although
there seemed to be no particular overt rationale for this.

Differences in the provision of services for older and younger adults with learning
disabilities are also evidenced in the data from Rohde and Farmer (1995). Their study
from the population of Westminster, showed that the reduction in number of older
adults in long-term institutional care was as a result of clients dying and hospitals being
shut to admissions, not to any increase in the number of people being moved into
community settings. This is very much at odds with the service philosophy of younger
adult services which are structured around providing clients with community
residential provision in accordance with the principles of the Community Care Act
(HMSO, 1990).
Fitzgerald summarises by saying that "Services for older people in general tend to be crisis-led and reactive rather than proactive. In comparison, the services provided for people with learning disabilities, with their emphasis on small group home accommodation and provision of day services, are expensive. Hence, the danger is that a person with a learning disability, who reaches the age of 65, may find their services cut dramatically from the level which they are used to. (Fitzgerald, 1998).

Speculation as to the cause of this discrepancy could lead you to examine diverse topics from politics, history, cultural norms, beliefs and stereotypes about ageing, to funding structures.

**Dementia. A Case for Specialist Services?:**

Much of the recent literature published in learning disability journals centres on the issue of dementia in this client group. It seemed to be the accepted case in the early nineties that people with Down syndrome, are especially at risk of developing dementia (usually Diseases of the Alzheimer Type) earlier than their non-learning disabled peers. Prevalence rates in people with Down syndrome have been reported as 5% in 41-45 year olds, and 45% in 56-60 year olds and that onset occurs 10-15 years earlier than in those people without Down syndrome (Visser, 1993, and Evenhuis, 1990 in Jordens, Evenhuis and Janssen, 1997).

Jordens, Evenhuis and Janssen's 1997 paper notes however that diagnosis in those with an IQ below 50 is difficult and that standard diagnostic criteria have therefore often not been applicable. This study of 94 people (with matched samples of people with and without Down syndrome) disagreed with previous studies in finding that there was not the expected linear decline in cognitive function within the Down syndrome group, but there was an effect of level of functioning across groups.

Devenny, Silverman, Jenkins, Sersen and Wisniewski (1996) in a study of 91 people, similarly found that "adults with DS (Down Syndrome) and mild to moderate mental retardation may be at lower risk for dementia during their fourth and fifth decades of life than previous studies found", and that in some cases of functional decline, other
alternative explanations were not excluded before diagnosis of dementia (such as thyroid dysfunction).

It would therefore appear that the issue is not entirely resolved, though it would seem wise to err on the side of caution and bear in mind a possible decline in functioning and increase in behaviours which may challenge services in those with Down syndrome (and other learning disabled clients) when care-planning in the client’s forties. This is when long-term decisions about the future suitability and flexibility of residential provision especially, should be made.

Parmelee and Lawton (1990) describe an “environmental docility” model, which predicts that people with dementia (and those with more profound disabilities) would be more at the mercy of their environment and it’s in built behavioural contingencies than more able peers. This would therefore mean that planners should be particularly careful about issues such as those raised in Kitwood (1993) where staff attitudes and the minutiae of the social environment are held to be critical. This is perhaps not a focus which is considered deeply in younger adult settings, rightly or not.

In discussing the basis of care for people with learning disabilities and dementia, Udell in Janicki and Dalton (1999) writes “on-going inclusion is extremely important because its absence can quickly lead to more rapid deterioration”. This on-going inclusion is defined as involvement in the individual’s pattern of everyday life. The implication being, that the individual should be supported to maintain their autonomy and use their skills, for as long as possible, not be removed from their usual pattern of life to be cared for in a new setting. The supporting of an individual to maintain a culturally valued pattern of life is also one of the tenets which underpins community services for younger adults.

Therefore the issue of whether to put in place supports for older clients who’s skills or physical well-being are faltering, (whether due to some organic pathology or not), is similar in nature to that of whether younger clients should receive the appropriate level of support defined by their skills and the severity of their disability. That argument has been resoundingly answered previously with a yes. The difference between these two
situations is a matter of the time-scale of change. Whereas a younger adults support will be reviewed every six months under a care-planing system, the client with dementia might require re-assessment on a weekly basis, but this is a practical, not a philosophical consideration.

**Examples from General Older Adult Services:**

The field of older adult service provision for people without learning disabilities holds examples of imaginative services which might shed light on approaches that could be useful in planning services for people with learning disabilities.

This is especially true for services for people with dementia. The special difficulties in caring for people, from the physical practicalities of building design, to the importance of valuing and respecting even the most disabled people have been discussed at length in this context. Work such as Dementia Care Mapping (Kitwood and Bredin, 1992) give a framework for assessing and providing quality care environments (with the focus on the social environment). The work of Olsen, Ehrenkrantz and Hutchings (1993) and others focus on the more practical and physical aspects of mobility and environmental design. Both of these approaches are equally applicable to specialist services for people with learning disabilities who also have dementia.

It is also worthwhile considering the work which has been done by various teams in several countries, on the provision of more homely, specialised units for people with dementia. Two examples are that of the “cantou” project in France (Ritchie et al., 1992) and the “domus” units in Britain (Lindesay et al., 1991). These projects are based on what seems to be a similar set of philosophical tenets as services for younger adults with learning disabilities. The list of aims being very much in line with providing help to individuals to maintain a valued role as a member of a community (of whatever size), providing help at a level to maintain or build skills and to value the members of the unit as individuals. Additional focus is aimed at the attitudes of staff, social distancing and the maintenance of skills and personal independence of residents and also the function of the unit as a home for life.
There are however, also major problems with some general older adult services, often this might be linked to societal views and the philosophy which has grown up around caring for older adults. Care-staff are generally poorly paid, often working in poorly resourced facilities, and sometimes poorly supported by management in terms of training and backup.

Woods (1996) notes that in learning disability services, a community home with eight residents might be seen as rather too large for the provision of appropriate care, but in general older adult services an eight bed home would not be seen as "economically viable".

Is Chronological Age Relevant?:
Data from a study examining dementia in people with learning disabilities have shown that intellectual deterioration can be independent of age. This study used rather gross testing instruments on a sample of hospitalised adults with Down syndrome (Hewitt, Carter & Jancar, 1985).

Fitzgerald (1998) notes that chronological age is not a good indicator of need, as most older adults in the general population manage to remain in their homes throughout their lives. Services for older adults with learning disabilities, if they are to hold to the principles of normalization, should therefore attempt to ensure this state of affairs occurs in this client group also.

The many interpretations of what constitutes an "older adult" also seems to suggest that there is more to this categorisation than chronological age. Mainstream services and literature generally use the 60 or 65 year cut off point. Literature in the learning disabilities field seem to have no widely recognised definition, some studies using 60, some 50, some even counting clients in their mid thirties as older adults. This confusion could be interpreted as an example of the heterogeneity of the client group we have come to label as older adults. Perhaps what has happened, is that we have been making a categorisation based on an irrelevant criterion, age.
Collins (1994) writes in a Values Into Action publication, that older adults with learning disabilities are often being denied what most would consider as normal opportunities because people believe that their age naturally increases their disabilities. Fitzgerald (1998) citing Walker, Walker and Ryan (1995) writes “staff working with older people with learning disabilities often have a strong belief that older people will be more dependent and less capable of learning new skills, despite lack of evidence to support that supposition.” This is a belief that the author has personally encountered in recent clinical work.

Walker et al. (1995) strongly point out that there is a need for individualised care for people, rather than prescriptive services defined by the label attached to a person, be that an older adult or an older adult who also has a learning disability.

Specialist Services or Integration into Generic Services?:
The extent to which younger adult services actually incorporate clients into the wider community is a topic still being debated. Although the principle of normalization is accepted, which therefore pushes us toward the increased use of community and generic resources, it’s application cannot be said to be without flaws and difficulties.

Sutcliffe (1989) found that despite the laudable aims of normalization, older adults with learning disabilities spent most of their out of home time with other older adults with learning disabilities. This situation was broadly similar across residential provisions and levels of ability.

Fitzgerald (1998) is of the opinion that “Setting up separate day centres for older people with learning disabilities, although it offers something different from regular day centres for people with learning disabilities, is not the way forward. Instead of making a separate resource, the staff team at the centre could be working toward including the older people in the services which already exist for older people in general.”

Integration of learning disabled children into mainstream schools and colleges may help to change societal views in time, but the case is less clear for older adult services at
present. Integration and acceptance of the current cohort of older adults with learning disabilities into mainstream services such as older adult day-hospitals and social clubs brings with it further difficulties due to the experience of the cohort of older adults already in these services. Their experience through most of their lives has been of the generally held belief that people with learning disabilities need to be segregated and cared for independently of the rest of society. The changes in ethos that were made concrete in the move to community care may have had little impact on the beliefs of older adults in current general services. Once people who were educated alongside learning disabled peers come to the age of needing such services, then integration in these settings is likely to become that much less problematic.

**New Ideas, Old ideas?:**

The philosophy of ‘ageing in place’ (Janicki and Dalton, 1999) is one which has recently been discussed. Authors have recently paid attention to this issue as a important factor in care-planning (especially as there is a move to care brokering). This idea has also begun to receive comment in influential pressure group literature such as that recently published by the Joseph Rowntree Foundation, Values Into Action and the Centre for Policy on Ageing which states that “care managers need to think about what needs the individual may have in 10-15 years time. . . . if a person’s physical needs change or increase, then the living environment and social support should be able to adapt accordingly.” (Fitzgerald, 1998). This idea would lead us into providing “homes for life” but ones which would be able to be flexible in the style and level of physical, nursing, educational, leisure and social care that they can provide.

A complete failure in this regard can be seen in the practice of closing long-stay hospitals to admissions and working with a reducing number of older clients as they die, without equivalent effort being put into providing alternative community provision for them as would be expected in a younger adult service. The care-planners in these cases have failed to plan services around clients’ future needs, or to adapt the services that are in place. This is what the philosophy of ‘ageing in place’ seeks to address.
Let us hope that these kinds of failures act as a catalyst for medium to long-term care-planning to take into account future physical, sensory abilities and adaptive behaviour of clients reaching the age at which decline becomes more likely.

Service philosophies with an in-built expectation of decline in later years, but holding to the aims of younger adult services, in education, maximising individual potential, independence, and adapting stable community provision over time to individual needs seems to be the way forward.

At the fundamental level this is not a huge departure from service philosophies used in younger adult services, except that there is a realistic understanding that the adaptive behaviour, physical and sensory abilities of clients with learning disabilities are likely to decline in later life. This is not to say that older adults should be denied the opportunity for education, employment, leisure and community participation, simply because general older adult services have unintentionally had this character, or because they reach an age at which they are seen to need to “retire”.

The major underlying themes for both younger and older adult services could be summarised as being individualised care, medium to long-term planning involving ‘ageing in place’ and a range of flexible services to cater for the equally heterogeneous client groups.

Discussion:
In summary, the author would argue that there is an absence of a clear rationale for basing services for older adults with a learning disability on a different philosophy than those for younger adults. The literature does not in the author’s view support a conclusion that there is a fundamental difference in the aspirations, needs, mediators of quality of life, or rights of older adults with learning disabilities. There is evidence that this group is as heterogeneous as their younger counterparts in everything but basic medical analyses. What differences there are, such as the earlier expression of dementia in people with Down syndrome, are more usefully seen as defining a need for a specialist service, but one that is still based on individual need and cannot be
rationally provided on the basis of age alone. Even if one of the more unusual models (such as the domus model) were to be implemented for this specialist service, the author believes that the fundamentals of the model remain close to those which underpin services for younger adults with learning disabilities.

Any differences in clients' preferences for activity or style of care, the author would argue (from an ecological approach) are an expression of the social history of individuals who make up the cohort of present older adults. They are not an expression of some characteristic of an "older adult" phenotype. These differences can be put in perspective by considering the different styles of care and cultural changes which the current cohort of older adults have witnessed, but this should be no different to the way in which we attempt to understand the individual differences of any service user of any age, culture, religion or social background.

One of the difficulties with this debate is that general beliefs about old age and older people can be negative, leading to reduced expectations for the services we provide, or expect for ourselves in the future. The author would argue that this is an important cultural bias that should be considered. People campaigning for the rights of people with learning disabilities will have faced similar negative attitudes while setting up community based services in the nineteen seventies.

If we are to learn from the past, service developers should fully involve service users in the development of services, both on an individual level through care management and also in a wider capacity through such initiatives as Quality Action Groups.

Using existing general older adult services as a template for this client group is unlikely to prove the best solution as there are criticisms of these services as they are currently believed to be under-resourced, may not be based on the most enlightened philosophies and beliefs, and the characteristics of the two groups of older adults do not bear much resemblance to each other when seen in a historical and ecological context.
Services should at root, be based on flexible individualised care taking account of personal preference, the principles of normalisation, with quality of life as a major indicator of effectiveness and not be based arbitrarily on age or stereotypes.

One of the conclusions that the author has come to consider is that developers could usefully look to the models used in younger adult learning disability services and see if they could be applied usefully to mainstream older adult services.
References:


Critically Evaluate Psychological Theories of Child Abuse and Their Contribution to Clinical Practice.

December 2000
Year 2
Critically Evaluate Psychological Theories of Child Abuse and Their Contribution to Clinical Practice.

Introduction:

The issue of child abuse (or maltreatment) has only been widely studied in the western world within the last twenty years. With this increase in research has come an awareness that child abuse is a pervasive social problem (Carr, 1999). However, the complexity of forms that abuse takes and the many cultural and social factors which impact upon the problem have slowed the formation of a theoretical base (Berliner & Elliott, 1996). Alongside these, ethical and practical difficulties in researching the topic and its ‘taboo’ nature within society have hampered efforts.

Researchers and clinicians have used a range of approaches from sociological through psychological and medical frameworks to try to predict, prevent and intervene effectively in cases of child abuse (Haugaard & Dickon Reppucci, 1988). Many theories which have been developed seek to understand specific aspects or forms of abuse (physical, sexual, neglect) rather than the entire range of abuse which occurs in society.

Child abuse can take many forms including non-accidental injury, verbal abuse, emotional abuse, neglect, physical and sexual abuse. These forms of abuse are by no means mutually exclusive as co-morbidity data is beginning to show (Carr, 1999; Ney, Fung & Wickett, 1994). However, in most theoretical accounts and in many studies, the different forms of abuse are considered as separate. Thus, for the purposes of this essay, models which endeavour to address child sexual abuse will be examined alone.

This essay considers the theoretical framework, evidence base and clinical implications of three widely used models of child sexual abuse. These different aspects are presented in consecutive sections for each of the three models.

Sexual abuse has been defined as “any sexual activity with a child where consent is not or cannot be given. . . regardless of whether or not the child understands the nature of the contact . . . or threat and deception are used” (Wolfe, 1985). Definitions have altered over time and between research groups, which has also hampered efforts to
compare data from empirical studies. More recently sexual abuse has been further subdivided into three areas, those being; direct sexual acts (molestation, penetration), indirect acts (enforced watching of pornography, genital exposure) and exploitation of a power differential between the abuser and the victim (Kolvin & Trowell, 1996 cited in Horne, 1999).

Other distinctions commonly made in the literature on child sexual abuse are those between extra-familial (by a person or persons outside the family) and intra-familial abuse (by a person or persons within the family). If the abuse is intra-familial and sexual in nature then the term incest has often been used. However there is an argument as to whether treating this form of sexual abuse differently than other forms of sexual abuse is valid, due to an implicit cultural hierarchy which would hold incest to be less serious than extra-familial sexual abuse (Finkelhor, 1984). The models presented in this essay have a shared focus of interest, that being intra-familiar child sexual abuse.

Child abuse in its many forms has possible life long consequences both for the victim and for the other people in the social network surrounding them. These consequences can be very serious, including the individual’s trauma, the transmission of abuse to the next generation, an increased risk of suicide, self harm, depression and other psychopathology (Polusny & Follette, 1995; Cicchetti & Cohen, 1995). Sexual abuse has also been linked to Post Traumatic Stress Disorder in child victims (Deblinger et al., 1989 cited in Becker, Alpert, Bigfoot, Bonner, Geddie, Henggeler, Kaufman & Walker, 1995). There are also societal consequences such as legal proceedings and court processes which may follow from cases of child sexual abuse.

Prevalence data, which has been gathered with ever more accuracy over the years is equally as concerning. Far from being an isolated phenomena exclusively experienced in disadvantaged groups in society, it now appears that child abuse in various forms is widespread throughout western societies (Vogeltanz, Wilsnack & Harris, 1999). Sexual abuse occurs with children of all ages (Carr, 1999). Some statistical data on the prevalence of child sexual abuse are given in the section which follows.
The Prevalence of Child Sexual Abuse:
As noted previously, the problem of child sexual abuse is far from an isolated and uncommon phenomenon. Because of the nature of child sexual abuse there are difficulties in researching its prevalence (Horne, 1999). These difficulties include the subjective nature of abuse experiences, non-standard definitions and criteria, difficulties in obtaining non-biased data from a sample, the lack of contact with statutory services which many abused children may have and the fact that most cases are not reported until well after the time of the abuse (Bentovim, Elton, Hildebrand, Tranter & Vizard, 1988). Despite these difficulties there is some general agreement between studies of the prevalence of child sexual abuse.

Child sexual abuse has been found to effect 15%-33% of females and 13%-16% of males in a sample designed to resemble the population of the U.S.A. (Polusny & Follette, 1995). Further studies have indicated rates of 4-60% of females and 2-30% of males (Smith & Bentovim, 1994 cited in Carr, 1999). Intra-familial which may account for 70% of abuse cases, has been found to be up to five times as common for female children than for male children, though boys are more likely to suffer extra-familial abuse (Carr, 1999).

The abuser has been found to be male in roughly 80% of sexual abuse cases (Smith & Bentovim, 1994 cited in Horne, 1999). Finkelhor (1984) reports father-daughter sexual abuse accounts for less than 33% of sexual abuse cases. Recent data suggests that offenders against children may begin to offend in their adolescence and not as previously assumed in adulthood (Murphy & Smith, 1996). Also against previous societal assumptions, it has been found that many offenders do not limit their offences to only one type of victim (Murphy & Smith, 1996). Only of late has research begun to look for cases of female perpetrated child sexual abuse.

When considering these data it is important to attend to how the sample was recruited and approached, when the research took place, what services were involved and the culture from which the sample was taken.
Child sexual abuse does not only occur by itself. Gillham (1994) found that in at least 15% of sexually abused children there was also evidence of physical injury. Co-morbidity between forms of child abuse has also been demonstrated by Ney, Fung and Wickett (1994) who found that 95% of their sample’s cases displayed a combination of forms of abuse. They found that a combination of physical neglect, physical abuse and verbal abuse had the greatest short term effects on young people. They also reported that neglect was an indicator of later physical and sexual abuse in many cases. This has implications for services in that it indicates that early intervention in families where neglect and verbal abuse occur would be beneficial. However, current funding and resource limitations can serve to limit services to only cases of clear physical or sexual abuse and may well be failing to prevent such escalation in some families.

Department of Health figures for 1994 (Browne, 1995) showed that 4 in 1000 children in England (0.4%) are listed on child protection registers. This together with estimates of prevalence in the region of 4-60% of females and 2-30% of males (Smith & Bentovim, 1994 cited in Carr, 1999) indicates that many children who are suffering sexual abuse (as it is defined by researchers) are not listed on child protection registers. This adds further weight to the need for clinicians working in settings outside Social Services to be aware of sexual abuse and have processes in place to refer as appropriate.

**The Psychoanalytical model:**

The psychoanalytical model of child sexual abuse comes from Freud’s Oedipal theory of the development of hysteria, in which accounts of father-daughter “incest” were dismissed as fantasies (Freud, 1896 cited in Waldby, Clancy, Emetchi & Summerfield, 1990). Freud’s original theory did hold these accounts as true, but is thought to have been withdrawn for various political and personal reasons (Benjamin, 1996).

These fantasies were held to develop from the phallic stage of child psychosexual development in which the female child becomes aware and envious of the superior male penis (penis envy). This leads to anger toward her mother and envy of her father whom she tries to seduce (the child seductress). The father is seen as an innocent in this theory (Glaser & Frosh, 1991).
In the psychoanalytical model the mother holds much of the responsibility for the abuse of her child, rather than the father. The abuse of a child has been proposed to be the mother acting out her incestuous desires for her father through the sexual relationship between her daughter and husband. Alternatively the abuse may result from the mother’s continued anger toward her mother and her consequent cessation of performance of her adult roles (including sexual), leaving her daughter to perform them in her place (Waldby et al., 1990). An alternative account holds that the female child of a rejecting mother may instigate abuse by turning to her father to satisfy a need for affection, or in revenge against her mother (Sanderson, 1991).

**Evidence for and against the Psychoanalytical model:**

The history of psychoanalysis has been based on case reports, examinations of individuals’ subjective experience, the development of theoretical concepts and the interpretation of these in single cases. Psychoanalytic theories have not been subjected to experimental testing until very recently. There seems little evidence other than persuasive case reports and theoretical discourses that the psychoanalytical model can stand up to scientific testing (Glaser & Frosh, 1991). However, recently researchers have attempted to conduct more methodologically sound and generalisable studies.

With regard to treatment effectiveness there is some limited evidence to support the use of individual psychotherapy with abuse survivors (Becker, Skinner & Abel, 1982; Sullivan, Scanlan, Brookehouser, Schulte & Knutson, 1992; both cited in Becker, Alpert, Bigfoot et al., 1995). There is also similar limited support for the use of group therapy based on the psychoanalytical model (Downing, Jenkins & Fisher, 1988 cited in Becker, Alpert, Bigfoot et al., 1995).

Evidence for the effectiveness of psychoanalysis with children, though not specifically those with a history of sexual abuse, comes from the Anna Freud Centre chart review study (Fonagy & Target, 1996). This study shows post-treatment improvements in a large proportion of cases of children with a range of anxiety, behavioural and mood disorders (Roth & Fonagy, 1996), though the study can be criticised for the lack of matched controls and selection procedures.
Two of the most basic assumptions of the psychoanalytical theory are that abuse is rare and that it is a product of fantasy. These are not supported by data quoted above (see "The Prevalence of Child Sexual Abuse" section) which shows that child sexual abuse has been found to be very real and not at all rare. Horne (1999) states that just 2% of allegations of child sexual abuse are unfounded, which goes against the assumption that the phenomenon is based in childhood fantasy.

The prediction that mothers who were abused as children may act with hostility to their daughters and seductively toward their sons has been supported by a study by Sroufe, Jacobitz, Mangelsdorf, DeAngelo and Ward (1985 cited in Alexander, Teti & Anderson, 2000). However, it would also be possible to explain the results in terms of traumatic conditioning and identification.

However, Freud's psychoanalytical theory was an early attempt to chart the psychosexual development of children. As such, it is impressive in that later research has supported the existence of sexuality, and progressive psychosexual development in young children (Glaser & Frosh, 1991).

**Clinical contribution of the Psychoanalytical model:**
The psychoanalytical account of child sexual abuse has been highly influential. It came early on in the history of the psychotherapeutic tradition in western European culture. The account led to a significant period of continued denial that sexual abuse was a reality in society, which therefore left child victims at risk. The ideas led to perpetrators being held not responsible for abuse, child victims not being believed and mothers also carrying responsibility for abuse. Glaser and Frosh (1991) state that these early ideas in themselves abused child victims further.

Because of the concepts upon which the model is constructed it has limited applicability. The model can be seen to explain intra-familiar abuse between father and daughter. The sexual abuse is held to act out unresolved "Oedipal complexes" in the abusing father, the child victim and her mother (Glaser & Frosh, 1991). Unfortunately it is difficult and problematic to apply the psychoanalytical concepts contained in the
model to sexual abuse involving a female perpetrator, male victim or abuse from outside the family (extra-familial abuse).

However, psychoanalytical attempts to analyze the effects of child sexual abuse on the individual have made contributions to an awareness of the impact of abusive experiences and the wide ranging effects which can follow them, such as later psychopathology (Cicchetti & Cohen, 1995). These attempts to understand the causes and consequences of child sexual abuse at the level of the individual have also highlighted the need for some form of therapeutic input after the event. Within the wider therapeutic tradition, techniques such as the interpretation of transference and counter-transference and the interpretation of dreams were applied in the treatment of people who claimed they had suffered sexual abuse.

The staged account of psychosexual development from Freud is still used alongside accounts of cognitive development in the assessment of children thought to be at risk (MacFarlane & Waterman, 1986).

It is interesting to note that Freud’s alternative theoretical account of incest did recognise the reality of claims of sexual abuse, but this was rejected by the culture in which he was working. Later psychoanalytical and feminist reinterpretations of the theory have attempted to place responsibility for the abuse on the father unlike in the original theory. They also attempt to draw parallels between the powerlessness of the child victim and mother with the inferior position women hold in western society (Waldby et al., 1990).

The Family Dysfunction model:
This structural systemic model uses family dynamics as it’s basis. In a move away from an individual psychoanalytical model there is an awareness of the importance of parental dysfunction and the child’s part in the dynamics of the family. The focus of the model is upon the pathology within the family as opposed to the pathology residing within any one individual. All of the members of the family are held to contribute to the maintenance of child sexual abuse within the “dysfunctional” family.
Following systems theory, the dysfunctional family is defined as a number of subsystems where the appropriate intergenerational boundaries and hierarchies are not in place and individuals fail to perform appropriate functions within the system. The dysfunctional family may also show overly rigid emotional rules, secrecy and inappropriate alliances between child and parent (Bentovim, Elton, Hildebrand et al., 1988).

There are specific patterns of structural dysfunction following from the above which may result in the sexual abuse of a child. The “incestrogenic” pattern is said to be when the parents cannot function in their adult roles or satisfy the other adult’s needs. They then turn to their children to fulfil these needs, which include sexual needs. A “possessive-passive” pattern is an exaggerated father dominated hierarchy in which the females hold no power and are thus structurally passive. The needs of the father are thus fulfilled by any of the family members. The final pattern is the “dependent-domineering” pattern where the mother is strong and the father is weak, resulting in the father turning to his weaker child for the fulfilment of his needs which are not being met by his wife (Mayall & Norgard, 1983). These characteristic patterns are described in different terms by Bentovim, Elton, Hildebrand et al. (1988) who distinguish between “endogamic” (conflict avoiding) and “disorganised” (conflict regulating) families, within which all of above and other patterns emerge.

Evidence for and against the Family Dysfunction model:
Evidence for a causal relationship between dysfunctional family dynamics and sexual abuse is lacking. There is some evidence that families in which a child has been sexually abused are ‘more disorganised’ and ‘less cohesive’ than the families of non-abused children (Elliott, 1994 cited in Berliner & Elliott, 1996). However, this is not unproblematic and there is little to establish whether the patterns described within the model (as presented above) do actually distinguish between families in which abuse does occur and families in which abuse does not occur (Masson & O’Byrne, 1993; Horne, 1999).
In putting forward a rival model of child sexual abuse, Finkelhor (1984) states that the
behaviour of mothers described within the family dysfunction model has not been
proved to be causal of abuse. In his interpretation, this maternal behaviour merely
reduces the inhibitory factors (as described in his model) acting against the occurrence
of abuse. Finkelhor claims that at most the family dysfunction model could be said to
describe patterns existing in families which maintain sexual abuse, not that the patterns
cause the abuse (Finkelhor, 1984).

The family dysfunction model might also be criticised for not being able to explain
cases in which a mother protects her daughter when abuse is suspected (Sanderson,
1991), other than to say that dysfunctional patterns did not exist in that family to start
with, which makes the occurrence of the abuse inexplicable within the model.

Some evidence for treatment effectiveness comes from the Great Ormond Street study
by Bentovim, Elton, Hildebrand et al. (1988) based on social worker ratings and client
questionnaires. This study found that for a 2-5 year follow up using professional
ratings there were improvements in family structure for 61% of the families who
attended family therapy within this model. 24% of the sample showed no change and
10% showed signs of getting worse. However, there was a significant drop out rate of
at least half. There was family splitting in roughly half, with only 14% of children
staying with both their parents by follow up. Consensus within the family about
whether abuse had occurred had changed, with many more families admitting abuse
and less being divided on the issue (Bentovim, Elton, Hildebrand et al., 1988). Ratings
of the children's sexualised behaviour and emotional disturbance both showed
reductions over the follow-up period compared to at the point of referral (Bentovim,
Elton, Hildebrand et al., 1988). However, at follow up, although in 69% of families no
further abuse had occurred, in 16% abuse had recurred. This does raise questions as
to whether more should be done to ensure safety for the child before attempting to
resolve family level dysfunction.

A study by Downing et al. (1988 cited in Becker, Alpert, Bigfoot et al., 1995)
compared treatment outcome in twenty-two girls aged six to twelve, between those
seen by counsellors working from a psychodynamic orientation and those working

54
from reinforcement theory. They found that both treatments brought about equally clinically significant changes (Becker, Alpert, Bigfoot et al., 1995).

**Clinical contribution of the Family Dysfunction model:**

This model is useful in the assessment and formulation of intra-familial abuse, as well as giving some direction to the development of family level interventions. Similar structural systemic models have been applied to other forms of abuse. Research conducted within this model offers ideas for the further development of parenting programs and interventions at the familial level (Bentovim, Elton, Hildebrand et al., 1988). Furniss (1991) describes an application of the model in designing meta-systemic “Primary Interventions” which have the aim of both keeping the child victim safe and of addressing the dysfunctional aspects of the family and aiming for reintroduction.

Due to its level of analysis, the goal of an intervention within this model will be in terms of family reunification and the creation of a safe and stable environment in which abuse will no longer occur (Carr, 1999). J. Hildebrand in Bentovim, Elton, Hildebrand et al., 1988 (pp300-319) provides a list of criteria against which a family can be rated to aid in decisions about the appropriateness of goals for interventions. There are also clear examples of goals and agendas for working with child victims of different ages, both males and females, and also mothers and fathers, all within a group context.

Another contribution that the family level analysis provided by this model has made is the consideration of the effects of child sexual abuse on the siblings of the abused child. The Great Ormond Street Study included ratings of behaviour and emotional disturbance in siblings as well as the abuse victim. The study showed some improvements in the sibling group at follow up (Bentovim, Elton, Hildebrand et al., 1988).

The work of Furniss (1991) also brings in useful ideas on the role that the professionals involved with the family take through their attempts to intervene. It is noted that professionals can become allied with members of the family or exclude them in unhelpful ways. In this way the family dysfunction model and later systemic theory
broadens the clinician's awareness of possible sources of unhelpful or abuse maintaining dynamics which may occur in the services around an abusive family.

**Finkelhor's Four Precondition model:**
Finkelhor's model of child sexual abuse (Finkelhor, 1984) is a multi-factorial model which attempts to give a precise framework within which factors at different levels of description from the individual level and the sociological level can be brought together and seen to be interacting. It attempts to explain both intra-familial and extra-familial sexual abuse and takes significant ideas from ecological and feminist approaches. The model looks at the role of the perpetrator of the sexual abuse and the risk factors associated with their actions across four preconditions (Bentovim, Elton, Hildebrand et al., 1988). The model draws on Finkelhor's theory of male gender socialisation.

The four preconditions are; factors related to motivation to sexually abuse; factors related to overcoming internal inhibitors; factors related to overcoming external inhibitors and factors related to overcoming the child's resistance. For abuse to occur, all four of these 'preconditions' have to be satisfied. Each precondition can be examined in terms of the individual and sociological levels of analysis. Each precondition and some of the risk factors associated with each, are specified within the model as below.

**Precondition 1: Motivation of an individual to be sexually interested in children and to sexually abuse.**
This precondition includes three components; emotional congruence, sexual arousal and blockage. Individual level factors include traumatic conditioning (where an adult with a history of abuse acts out and repeats the abuse), arrested emotional development, need for power and control or inappropriate attention to arousal cues. Sociological factors may include where the beliefs held by the family state that the sexuality of children is equivalent to that of adults or that sexual relations in the family is 'normal' or expected. They may also involve the male need to be dominant, the male tendency to sexualise emotional needs and sexualised portrayal of children in the media. This precondition might also involve the blockage of normal adult sexual
outlets, such as the failing of a adult sexual relationship to cater for the abusers sexual needs (Hartman & Burgess, 1989).

*Precondition 2: Overcoming internal inhibitions to putting the above into action.*
This precondition may involve the individual factors of drug or alcohol abuse, psychotic illness, dementia, or cognitive strategies such as rationalising, normalising, or denial of the traumatic effects of sexual abuse. Sociological factors may include the tolerance of sexual interest in children, an ideology of patriarchal dominance and a social tolerance for violence committed whilst under the influence of alcohol (Hartman & Burgess, 1989).

*Precondition 3: Overcoming external inhibitions to putting the above into action.*
This may involve individual factors such as a lack of protection or supervision for the child, unusual access to the child, over-crowding or rigid male dominant roles and female compliance in the family. Sociological factors may include inequality of women, lack of social support for mothers and the erosion of a family based ideology (Hartman & Burgess, 1989).

*Precondition 4: Overcoming the child’s resistance to abuse.*
This may involve individual level factors such as a particular vulnerability of the child, deprived, emotionally immature, physically or mentally handicapped or without knowledge of sexual matters. Threats and other forms of persuasion such as bribes and rewards might also be used. Sociological factors may include social powerlessness of children and lack of sex education.

**Evidence for and against Finkelhor’s model:**
The model is essentially multi-theoretical in that it brings together findings on which factors contribute to child sexual abuse, what is known of the individual psychology of abusers and ideas from sociology. It is therefore of great heuristic value in an applied setting (Sanderson, 1991). The model incorporates the finding that “*psychological structures emerging from the experience of sexual abuse have a role in the development of aberrant sexual motivation and disinhibiting responses*” (Hartman & Burgess, 1989).
Some evidence that the model can predict child victims’ ability to recover from abuse comes from studies which show a correlation between the abusers’ style (degree of violence and the specific way in which the four preconditions are met) and the victim’s recovery (Finkelhor, 1984; Tufts, 1984 cited in Hartman and Burgess, 1989).

Evidence on treatment effectiveness in programs based upon this model is lacking. The assumptions and hypotheses generated within the model may well have been supported by some studies of eclectic individual and group work including those termed “educational” interventions, but it is difficult to make a conclusion on this point due to the poor accounts given in such studies of the procedures used or the theory upon which the interventions were based (Becker, Alpert, Bigfoot et al., 1995). However, looking for evidence to support this particular model is in a way missing the point. It was designed as a framework in which the disparate and often contradictory findings from risk factor and forensic psychological studies could be brought together and seen to be contributing to cases of child sexual abuse.

Thus it remains a multi-theoretical descriptive framework which has itself emerged from findings gathered from forensic and risk factor research conducted up until 1984 when the model was published (Finkelhor, 1984). As such it can be of great value (see the following section). What would be needed to raise it’s standing are studies which state hypotheses based specifically upon the model and then seek evidence for or against them. For instance, that in a random and representative sample of cases of child sexual abuse all of the four preconditions are satisfied, and that in other cases (e.g. of physical abuse) they are not. Other studies might look to see if interventions designed to alter or address a specific factor or precondition have an effect on the expression of sexual abuse. However all such studies would have to overcome the ethical and practical hurdles discussed previously (see “Introduction” and “Prevalence of child sexual abuse” sections).

Clinical contribution of Finkelhor’s model:
Carr (1999) views Finkelhor’s model as a useful “general framework” in the assessment of cases of child sexual abuse. The model has been widely used and
appears in texts on the subject of child sexual abuse across professional boundaries. It provides a more structured account than previous additive risk factor models which attempt to define a checklist for the assessment of families (Finkelhor, 1984). As well as it’s applicability to the assessment and formulation of cases, it has some applicability to treatment approaches, though this has yet to be fully explored as described above.

Finkelhor’s model is clear in attributing responsibility for any specific act of abuse to the perpetrator. Although the mother may be involved at the level of not providing sufficient protection or supervision for the child (Precondition 3) she is not responsible for the abuse. In the same way, although certain child characteristics have been linked to sexual abuse, the child is not held responsible for the abusive acts as these only come into action at Precondition 4 where they may weaken a child’s ability to defend themselves against the abuser. This is a change from both the psychoanalytical and family dysfunction models, which do attribute responsibility for the abuse at least partially onto the child or the mother when the act is carried out by the father.

The Four Precondition Model also has the advantage over the other models presented in this essay of being able to address cases of extra-familiar sexual abuse. This is because throughout the model the individual psychology of the abuser and the conditions both internal and external surrounding the abuse are brought together. Extra-familial abusers can be seen to have satisfied the earlier preconditions prior to attempting sexual abuse. The process known as grooming (where an abuser befriends and desensitises a child and possibly the family to sexual contact) can be seen as falling within Preconditions 3 and 4.

This contribution is very valuable as prevalence data shows that extra-familial abuse is also a widespread phenomenon (see “Prevalence of Child Sexual Abuse” section) and one which may also be under-reported at present. Because the model does not distinguish between extra and intra-familial abuse it runs contrary to patriarchal and judicial system values which seem to hold intra-familial abuse as being less severe, damaging or reprehensible (Sanderson, 1991).
Summary and Conclusions:
Despite the interest in researching the area of child sexual abuse there are still many questions. Accurately describing the risk factors involved, the prevalence across our society and the correlates of child sexual abuse is not yet complete (Polusny & Follette, 1995). For instance there is a widely held belief that children are more likely to suffer abuse (not just sexual abuse) in step-families. This idea has received support from large scale studies such as the National Incidence Study (National Center on Child Abuse and Neglect, 1981). However this and other similar prevalence studies, neglected to include step-parents not living at home or control for socio-economic status between the step family and natural family groups (Giles-Sims & Finkelhor, 1984). This example demonstrates some of the difficulties inherent in child abuse research which make any certainties very elusive.

The Child Abuse and Neglect Working Group of the American Psychological Association (Becker, Alpert, Bigfoot et al., 1995) having reviewed contemporary studies of treatment effectiveness in sexual abuse, concluded that “many of the studies do not adequately explain their procedures and do not utilize adequate methodological controls (e.g. control group and random assignment)”. This makes it difficult to conclude whether hypotheses derived from the models discussed in this essay have been supported or not, hence the lack of evidence presented to support both Finkelhor’s Four Precondition model and the Family Dysfunction model. However in summary the working group concluded that outcome research with child victims and adults abused as children “suggests that treatment is effective: however, comprehensive and carefully designed studies have not been done.” (Becker, Alpert, Bigfoot et al., 1995).

In conclusion then, as prevalence data shows (see “Prevalence of Child Sexual Abuse” section) the problem of child sexual abuse is a serious challenge to our society. Morally it is a problem which scientist-practitioners must develop clear approaches to addressing. As discussed in this essay, diverse theoretical accounts have been developed but evidence to support specific hypotheses and to gauge the effectiveness of treatments strictly based upon them is lacking.
References:


Core Older Adults Essay

The ageing process gives rise to many inevitable psychological and physical changes. Discuss.
The ageing process gives rise to many inevitable psychological and physical changes. Discuss.

1) Introduction:
Ageing is a complex and multiply determined process showing large individual differences (Woods, 1996). To decide whether age related decline is inevitable, we must assess whether decline occurs in all people, across all skills, and can not be halted or remediated. To this end, Section 2 discusses some pertinent definitions and methodological issues in the field. In Section 3, demographic data are summarised to provide a broad picture of ageing in the United Kingdom. After this research evidence, which delineates patterns of ageing and bears upon the inevitability or not of decline, is discussed. Separate sections deal with physical health and the occurrence of dementia (Section 4), mental health (Section 5) and cognitive performance (Section 6). A summary and conclusions section completes the essay (Section 7).

2) Definitions and Methodological Considerations:
The terms ‘older adult’ and ‘old age’ are generally applied to people with a chronological age of more than 60 or 65 years. Notable heterogeneity within groups of older adults in cognitive function (Rabbitt, 1993 cited in Stuart-Hamilton, 1996), physical health, functional ability, social activities means that chronological age can be criticised as lacking in descriptive power. This criticism is backed by chronological age’s poor correlation with measures of biological, psychological and social ageing (Bond, Coleman & Pearce, 1993).

An alternative to chronological age is ‘social age’, which is based on social norms of behaviour across the life-span (Stuart-Hamilton, 1994). However, in the author’s opinion it is limited as it is largely sub-culture and cohort specific. An alternative construct could be based upon a combination of functional, physical and mental health indices. Such a definition however, though more sensitive to group heterogeneity, would be too complex to be workable. Hence, although chronological age is not sufficient to describe an individual’s ageing, it remains important as it indicates the likely distribution of performance for average people of that age, and therefore allows reasonable comparison.
The process of ageing does not begin as a person reaches an arbitrary chronological age. It is active even in early life and Coleman (1993) notes that some authors have opined that it is the same process as maturation (likening the process of massive neuronal loss in the neo-nate to slower progressive loss through adulthood). The diametrically opposed view would be that ageing is a process of inevitable and universal decline, leading to physical and mental ill health, loss of cognitive performance and dementia. Another perspective (the Selective Optimisation with Compensation Model) holds that any age related decline is compensated by the strengthening of alternatives, leading to positive outcomes such as deeper understanding, wisdom and the ability to cope with seemingly overwhelming losses (Baltes & Baltes, 1990). These varied standpoints are important to consider when assessing research bias.

Before assessing evidence for age relate decline, some methodological issues need to be explored. These issues include cohort effects, sampling effects and the third variable problem. Cohort effects are changes in factors such as education, health, experiences and culture between the individuals within different age-group samples in a study (Woods, 1996). Cohort effects will also come into play when comparing findings from different studies and especially studies from different countries. The impact of numerous unmeasured variables which are correlated with the passage of time, may either over-represent individual decline (if the changes over time were favourable) or under represent individual decline or even reverse it (if the changes were unfavourable). Sampling effects are bias in the selection of participants for groups (selecting only working people for an IQ study) or for example, due to differential drop out rates over time between those with high and low IQ scores (Birren & Warner-Schaie, 1996). The third variable problem occurs when attempting to attribute causality and is due to the fact that any change found in a dependent variable may not be due to the independent variable measured, but due to changes in an unmeasured 'third' variable.

Two study methods have been popular in the field. Cross-sectional studies compare data from different age-group samples at one point in time to infer change over time. They are open to cohort effects, sampling effects and the third variable problem. They
are popular due to their relative simplicity. They will attempt to maintain power by using large samples, well matched groups on a number of relevant variables or random sampling. Longitudinal studies take measures from the same individuals across time and are more costly in time and resources. They largely avoid cohort effects (though not entirely) and are still open to third variable and sampling problems. They provide the best evidence for age related change in individuals. These issues are important as demonstrated by the fact that longitudinal studies show less age related decline in cognitive function than comparable cross-sectional studies (Stuart-Hamilton, 1996).

3) A Picture of Ageing in the U.K:
In the last century, the U.K. has experienced a growth in the proportion of its population in old age. This is sometimes referred to as ‘greying’ of the population (Warnes, 1989) and has been attributed to two factors. Firstly, longer life expectancy from birth due to accident prevention and a reduction in poverty and its associated risk factors. Secondly, longer life expectancy in later life, due to medical advances in the screening and management of physical illnesses. In recent years the increase in life expectancy of older adults that has been most evident (Figure 1). (Office for National Statistics, 2001).

<table>
<thead>
<tr>
<th>Life Expectancy at Birth</th>
<th>1911</th>
<th>1997</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>50 yrs</td>
<td>75 yrs</td>
</tr>
<tr>
<td>Women</td>
<td>54 yrs</td>
<td>80 yrs</td>
</tr>
</tbody>
</table>


However, the ‘greying’ trend has not been of the catastrophic proportions predicted twenty years ago (Bond, Coleman and Peace, 1993) and it is also set to continue at a much lower rate than predicted in the 1980’s (Office for National Statistics, 2001). Implicit in the idea of a ‘greying’ population is the suggestion that the population is under financial stress from the needs of a dependent, non-working older group. However, 50.3% of men aged 60-64 are still economically active (Figure 2). The dramatic fall in economic activity in men over 65 yrs (to 7.9%), likely indicates the strength of workplace pressure and social norms rather than men’s wishes. Income figures for women are similar though lower across all age groups.
The distribution of assets favours adults near retirement age (Office for National Statistics, 2001). However, the majority of Social Security expenditure is aimed at the needs of older adults (Figure 3).

So in summary, there is a trend in the U.K. for an increasing proportion of people to be over 60 years of age. Most older adults are likely to have assets, built up through their working lives, and an income until the age of retirement (Office for National Statistics, 2001). The majority will not earn an income after the age of retirement, and a large proportion of social security and public health funding will be needed by this group (Office for National Statistics, 2001).

4) Evidence for Age related changes in Physical Health and Dementia:
There is overwhelming evidence from medical studies that many of the body’s functions degenerate progressively with advancing age. For example, age related changes in the visual system range from the thickening and yellowing of the cornea to loss of cell density in the colour-sensitive parvocellular visual pathway (Weale, 1982;
Lerman, 1984; Ahmad & Spear, 1993; cited in Kline & Scailfa, 1996). Such physiological changes result in functional changes including slower glare recovery and reduced acuity in low light (Kline & Scailfa, 1996). Similar deterioration is evident in the auditory system. However, audiometric data do not map neatly onto reported hearing problems in older adults (Garstecki, 1987 cited in Kline & Scailfa 1996). This has been taken to indicate that individuals compensate for sensory deterioration (see also Section 6), and that exogenous or environmental factors are powerful in comparison to age related changes, in determining actual sensory problems in older adults (Kline & Scailfa, 1996).

When considering whether ageing brings *inevitable* change, the question ‘How many older adults will be suffering from a disability or a health condition?’ is important. By the World Health Organisation’s definition of health which is “a state of complete physical, mental and social well-being, and not merely the absence of disease or handicap” (Deeg, Kardaun & Fozard, 1996. p130) most older adults would not be classed as healthy. This however, is a very tight definition and is not particularly informative as the author was unable to find comparable data as to what proportion of younger adults would also fall outside of this classification. There is also overwhelming medical evidence of changes in the prevalence of various specific diseases and physical conditions with age, usually but not exclusively to the advantage of the young (Warnes, 1989).

Back pain is a much researched and very significant health condition occurring across the adult population. It will serve as an example of health conditions not directly linked to mortality. In the U.K. it is estimated that back pain prevalence is higher in men than women and it affects 70% of all people by the age of 60. Chronic back pain (lasting all year) also increases with age, rates being 1 in 12 people between the age of 25 and 44 years, and 1 in 3 men and 1 in 4 women over 60 years (Office for National Statistics, 2001). These data illustrate that a significant proportion of older people have to cope with the demands of health conditions, and for many this may be a chronic situation.
Similarly, cross-sectional studies have shown a robust trend for decreasing functioning with age in the areas of cardiovascular, neurological and metabolic function (Pendergast, Fisher & Calkins, 1993 cited in Deeg, Kardaun & Fozard, 1996). It could be argued that longitudinal data will be increasingly important in measuring age related changes in physical health as there have been changes in the social norms and amount of exercise people undertake in and out of work. Such changes may impact on physical health trajectories and affect the age related changes found in previous cross-sectional studies.

There is also evidence that older people may appraise illness and disability differently than their younger counterparts. For example, two cross sectional studies (Levethal, 1984; Cassileth, Lusk, Strouse, Miller, Brown, Cross & Tenaglia, 1984 cited in Deeg, Kardaun & Fozard, 1996) found that older patients reported lower levels of illness related shame, fear or anger than matched younger patients. Cohort differences in health expectancy, health-risk knowledge and previous experience of illness were implicated. This could be further investigated by longitudinal studies to assess change in individuals over time.

So, there are correlations between mortality, onset of many specific medical conditions, reduction in measures of physiological function and increasing age, but are these inevitable? Modifiable risk factors for many diseases have been found to still be active in older adult patients (Fries, Green & Levine, 1989 cited in Deeg, Kardaun & Fozard, 1996). Thus older adults can impact upon their health status by taking similar risk-reducing steps as younger people. There is also evidence from both cross-sectional and longitudinal studies that older adults can benefit from maintaining moderate levels of exercise (Deeg, Kardaun & Fozard, 1996). Men in both the older and middle age categories were found to benefit from exercise with regard to cardiovascular functioning (Donahue, Abott, Reed & Yano, 1988 cited in Deeg, Kardaun & Fozard, 1996). So there is evidence that some physiological changes can be ameliorated by training, and whilst this does not mean decline is not going to occur (see back-pain, above), it does mean that marked decline will not be universal.
Reviews of major dementia prevalence studies from the U.S.A. and Europe concur that the rate of dementia (of Alzheimer and Vascular types) increases almost exponentially every 6 years with the chronological age of the sample (Ritchie, Kildea & Robine, 1992), see Figure 4.

*Figure 4: Prevalence of Dementia by Age*

<table>
<thead>
<tr>
<th>Study / Review</th>
<th>60-64</th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85-89</th>
<th>90-94</th>
</tr>
</thead>
<tbody>
<tr>
<td>EURODEM Study</td>
<td>-</td>
<td>0.3</td>
<td>-</td>
<td>3.2</td>
<td>-</td>
<td>10.8</td>
<td>-</td>
</tr>
<tr>
<td>Ritchie et al. Review</td>
<td>0.8</td>
<td>1.4</td>
<td>2.6</td>
<td>4.7</td>
<td>8.7</td>
<td>15.8</td>
<td>29.0</td>
</tr>
<tr>
<td>ECA Study</td>
<td>-</td>
<td>-</td>
<td>2.9</td>
<td>-</td>
<td>6.8</td>
<td>-</td>
<td>15.8</td>
</tr>
</tbody>
</table>

Source: Adapted from Gatz, Kasl-Godley & Karel (1996) p375.

The prevalence figures quoted are from studies using large community samples, or reviews of such studies. As well as demonstrating that the incidence of dementia increases with chronological age, these figures also show that for an average individual the chance of developing dementia is <10% until the age of roughly 85 years, and hence that the majority of older adults do not develop dementia and that it is not an *inevitable* part of the ageing process.

Age related physiological decline and the increasing occurrence of illness are important in themselves and also through their impact on mental health, social functioning and cognitive change (Stuart-Hamilton, 1996). The salience of psychological (such as coping), social and environmental factors associated with changes in functional ability are brought into focus by the finding that physiological measures of health status (blood pressure, lung capacity) were found to be less related to mortality than change in functional ability over time (Manton, Stallard, Woodbury & Dowd, 1994 cited in Deeg, Kardaun & Fozard, 1996). Functional decline has also been found to be related to psychological measures such as feelings of uselessness and social non-participation (Grand, Grosclaude, Bocquet, Pous & Albarade, 1988 cited in Deeg, Kardaun & Fozard, 1996) which are implicated in mental health conditions (Section 5). Similarly, the worth of assessing psychological constructs because of their bearing upon the occurrence of organic illness is demonstrated by the finding of a link between lower cognitive test performance and later development of dementia (LaRue & Jarvik, 1987 cited in Gatz, Kasl-Godley & Karel, 1996) in longitudinal studies.
5) Evidence for Age related decline in Mental Health:

Good evidence bearing upon this issue comes from several large scale studies carried out into the distribution of psychiatric and psychological disorders in older adult populations using standardised criteria (Epidemiologic Catchment Area Survey [ECA]; Established Populations for Epidemiologic Studies of the Elderly [EPESE] cited in Gatz, Kasl-Godley & Karel, 1996). However, these studies were cross-sectional and may misrepresent age related change in individuals due to cohort effects (Section 3).

Using data from a variety of sources including those mentioned above and United States government data, Gatz and Smyer (1992 cited in Gatz, Kasl-Godley & Karel, 1996) estimated that 22% of adults over 65 would be classified as having a mental disorder (including both cognitive and emotional disorders). Gatz, Kasl-Godley and Karel (1996) point out that this is in line with the estimated 17-22% proportion of younger adults who suffer similarly (Kazdin & Kagan, 1994 cited in Gatz, Kasl-Godley & Karel, 1996). This evidence from large scale studies, suggests that the proportion of adults suffering from mental disorders is not largely effected by chronological age and therefore that mental ill-health is not an *in evit able* or universal part of ageing.

However in this comparison, bear in mind a cohort effect between the studies of the younger and older adults. It could be argued that the younger adults figure is artificially higher, for example due to the increasing acceptability of reporting problems, or an increasingly stressful urbanised life. It could also be argued that the figure for older adults is artificially high due to the impact of physical health on mental health symptoms (e.g. reactive depression) or the inappropriate nature of the questionnaires and criteria in this group.

Within the picture created by this group data there remains the possibility that the prevalence of specific disorders or their presentation may change with age. What is the evidence that this is so? From the ECA study (which used a diagnostic interview schedule) the evidence is that a smaller proportion of older adults (65yrs+) suffer from *clinically defined* depression or dysthymic disorder than younger adults (25-64yrs) (Figure 5) and that this result holds for both genders (Regier, Boyd, Burke, Rae, Myers, Kramer, Robins, George, Kamo & Locke, 1988 cited in Gatz, Kasl-Godley & Karel, 1996). However a much larger proportion of the sample had some depressive
symptoms but not enough to satisfy clinical diagnostic criteria (27% for adults 65yrs +). Rates of depression in older adults vary greatly between studies (Woods, 1996). For example, in a large study (N=1000), Lindsay, Briggs and Murphy (1989 cited in Woods, 1996) found rates to be 4.3% for severe depression, and 13.5% for moderate or mild depressive symptoms.

*Figure 5: One Month Prevalence of Mental Disorders by Age in the United States.*

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Gender</th>
<th>Age 25-44yrs</th>
<th>Age 45-64yrs</th>
<th>Age 65yrs +</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressive Disorder</td>
<td>Men</td>
<td>2.2 %</td>
<td>1.2 %</td>
<td>0.4 %</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>3.9 %</td>
<td>2.6 %</td>
<td>0.9 %</td>
</tr>
<tr>
<td>Dysthymic Disorder</td>
<td>Men</td>
<td>2.8 %</td>
<td>2.0 %</td>
<td>1.0 %</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>5.1 %</td>
<td>5.4 %</td>
<td>2.3 %</td>
</tr>
<tr>
<td>Anxiety Disorder</td>
<td>Men</td>
<td>4.7 %</td>
<td>5.1 %</td>
<td>3.6 %</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>11.7 %</td>
<td>8.0 %</td>
<td>6.8 %</td>
</tr>
</tbody>
</table>


The EPESE study (which used symptom checklists) data suggests that the highest rates of depressive symptoms occur in young adults and adults over the age of 75yrs. Taking these two types of data together (clinical diagnostic criteria data and symptom checklist data) suggests that although symptoms may increase in middle to older age, clinical disorder prevalence as defined by diagnostic criteria does not. However, caveats include the fact that both studies were cross sectional (see Section 3), and that the data may suffer from the lack of well standardised diagnostic instruments for older adults (Woods, 1996). Thus the data may reflect cohort effects as well as changes in the presentation of disorders in older adults and actual changes in the prevalence of disorders.

There is some evidence that the occurrence of depressive symptoms co-varies with age and sex. Wallace and O’Hara (1992 cited in Gatz, Kasl-Godley & Karel, 1996) using a combined cross-sectional and longitudinal method and a sample of rural living older adults, found that men and women score similarly over the age of 80 years, whereas in younger age groups women report more depressive symptoms.

Older adults who present with depressive symptoms may have had previous episodes of depression throughout their lives, or have developed depression for the first time in
old age. In the ECA study the median age of clinically defined depression onset was 25 years of age (Burke, Burke, Regier & Rae, 1990 cited in Gatz, Kasl-Godley & Karel, 1996). This suggests that more cases of depression have an original onset in young adulthood than in older adulthood, though an increased risk (higher chance of onset) was also noted above the age of 89 years.

A further finding which deserves notice due to its relation to risk comes from a study by Conwell (1994 cited in Gatz, Kasl-Godley & Karel, 1996). He reported an increasing risk of suicide from the age of 60 to 85 years in white American males, especially if they are living alone or suffer from physical illness. Though the impact of cohort effects and cultural difference should not be underestimated in this finding (suicide risk being closely linked to availability of firearms, rural dwelling etc. and these being very different in the U.S. and the U.K.) this is an issue worthy of further investigation. Looking for links between suicide risk, functional decline, health variables, psychological factors such as coping and social or formal support would be the next step in this area.

Anxiety disorders are just as prevalent as depressive disorders, and in a sample of urban older adults approximately 13% had a phobic or generalised disorder (Lindesay, Briggs & Murphy, 1989 cited in Woods, 1996), though these disorders have received far less research attention. Roth and Fonagy (1996) cite several large sample studies and conclude that lifetime prevalence rates are approximately 11% for phobia and around 5% for generalised anxiety disorder for samples not including older adults. These data, though difficult to compare for methodological reasons (see Section 3), seem somewhat similar. Data from the ECA study indicates that anxiety disorders usually have an onset in earlier adulthood, with only 3% having an initial onset after the age of 65 years (Blazer, George & Hughes, 1991 cited in Gatz, Kasl-Godley & Karel, 1996). Again, this finding should be viewed with some caution as the presentation of anxiety in older adults might not be such that it is picked up by anxiety measures, which like their counterparts in depression are often standardised only against samples of young adults or with the exclusion of the very old.
Schizophrenia, which most commonly has an onset in early adulthood has been reported more infrequently in older adults. Due to differences in its presentation in older adults it has been referred to as paraphrenia by some authors. Paraphrenia involves similar paranoid delusions as in schizophrenia, whether combined or not with hallucinations, and there is less emphasis on the appearance of thought disorder than in schizophrenia (Gatz, Kasl-Godley & Karel, 1996). There is some evidence that the gender bias which is has been robustly found in younger adult schizophrenics (males being more often effected than females) does not hold in older adults (Rabins, 1992 cited in Gatz, Kasl-Godley & Karel, 1996). There are some difficulties with this area of research however. Firstly, studies have generally been conducted using small samples due to the difficulty in accessing sufficient numbers of similarly diagnosed patients. Secondly, delusions, hallucinations and circumlocutory speech (which can be misidentified as thought disorder) may occur in people who are suffering from dementia, even in its early stages before any gross cognitive impairment is evident (Woods, 1996).

With regard to wider mental health (rather than specific mental disorders) Cassileth, Lusk, Strouse, Miller, Brown, Cross and Tenaglia (1984 cited in Deeg, Kardaun & Fozard, 1996) found evidence from a large regional sample, that older adults showed less physical illness associated distress than younger people matched for illness severity and other measures (see also Section 4). The study also found that illness associated mental health in older adults was poorer in the first three months after diagnosis than after that time, indicating that psychological adaptation to illness does occur to some extent.

However, there is also some contrary evidence that older and younger adults cope similarly with physical illness. Similar patterns of physical illness related depressive symptoms were found in a study of older adults (Kennedy, Kelman & Thomas, 1990 cited in Deeg, Kardaun & Fozard, 1996) and similar studies of other age groups (Von Korff, Ormel, Katon & Lin, 1992 cited in Deeg, Kardaun & Fozard, 1996). These studies found that a reduction in activities of daily living and an increase in the number of illness conditions was more predictive of depressive symptoms than was the person’s objective baseline health status.
Similar studies to these last two, using more sensitive measures of psychological variables and U.K. samples, would be able to clarify and explore this area. Such research might have significant impact on the approach to pre and post-operative care of older adults which, in comparison to the similar care of children, has received relatively little attention.

6) Evidence for Age related decline in Cognitive Function:
Before looking at the evidence for age related cognitive change, it is important to consider the context in which it has been derived. Many researchers have concluded that there is more variability in samples of older adults than their younger counterparts, which makes the delineation of age related cognitive change more difficult (e.g. Rabbitt, 1993 cited in Stuart-Hamilton, 1996). There is also variability in the patterns of change reported between different aspects of cognitive performance. One of the most common distinctions made in the literature is that between ‘fluid’ and ‘crystallised’ intelligence. Tests of crystallised intelligence are typically verbal and knowledge based, biased toward western cultural definitions and show little if any age related decline (Stuart-Hamilton, 1996). Fluid intelligence tests involve solving novel (often visuo-spatial) problems which do not rely on and cannot be solved using formal training or a cultural knowledge base. Such tests have been found in the majority of studies to show quite significant age related change and complexity effects (Stuart-Hamilton, 1996).

Another contextual criticism is that research which attempts to measure age-related cognitive decline using psychometric tests is flawed because the tests and paradigms were created for the measurement of the young and the prediction of future ability within a developmental framework. Such laboratory based research has also been criticised for its lack of naturalism and hence its poor validity when attempting to explain performance in everyday life (Coleman, 1993). Evidence for this standpoint includes findings from reputable research groups which are hard to reconcile with everyday observations. For example, older adults were found to perform 1¼ standard deviations lower than younger adults on a group of fluid intelligence tests (Salthouse, 1992 cited in Stuart-Hamilton, 1996). If these results were representative of everyday
cognitive functioning then older adults should resemble adults with learning disabilities, which they generally do not.

The crystallised - fluid intelligence distinction has been criticised as being limited in its specificity (Birren & Warner Schaie, 1996). Researchers therefore, moved on to use a variety of more closely defined cognitive constructs, taken again from a child and general adult psychometric research base. Some of the most notable research of this type has been carried out by K. Schaie and colleagues in the Seattle Longitudinal Study (Schaie, 1993, 1994, 1995 cited in Birren & Warner-Schaie, 1996). This study followed people aged 25-88, took psychometric measures of five primary mental abilities and then derived scores on six latent constructs from them. Warner-Schaie summarises the data by saying that “longitudinal decline is noted by the mid-50s for Perceptual Speed and Numeric Ability, by the late 60s for Inductive Reasoning and Spatial Orientation, and by the late 70s for Verbal Ability and Verbal Memory” (Warner-Schaie, 1996, p270). From this large sample, the evidence is that after cognitive gains up to the mid 30s and a period of stability until the late 50s, cognitive decline becomes statistically evident in the 60s and continues from this age on. The advantages of these series of studies lies in their combined methodology which took both cross-sectional and longitudinal measures across a large sample (see Section 3).

Studies based upon the measures developed by Wechsler, for example the WAIS-III (Wechsler, 1997) have found similar evidence. Improved performance between the ages of 40 and 61 was found on subtests loading onto the Verbal IQ, and a complexity effect (decline on complex items, improvement on simple items) was found for those loading on the Performance IQ (Sands, Terry & Meredith, 1989 cited in Warner-Schaie, 1996).

To put this evidence into real life terms, Schaie (1989 cited in Warner-Schaie, 1996) found that in a community sample, although nearly all subjects had declined somewhat on at least one of the primary mental abilities measured by the age of 60, none of the subjects had declined on all of the measures by the end of the study at age 88 (see Figure 6). From the Seattle Longitudinal Study data the authors suggest that greater
declines were found in those abilities less central to an individual’s work or life experiences, or those less practised (Warner-Schaie, 1996).

As discussed, there are large individual differences in the exact cognitive skills which decline, their trajectory of decline and the age at which these changes occur. This suggests that inevitable may be an inappropriate description. In addition, some data shows that illnesses and impairments alter the trajectories of decline in cognitive skills. Hearing impairment has been found to be linked to greater decline in Verbal Meaning, but also with preserved (better and to a later age) performance on Spatial Orientation. Likewise, visual impairment has been linked to the postponement of decline in Verbal Meaning and Spatial Orientation (Gruber-Baldini, 1991 cited in Warner-Schaie, 1996). The same authors also report a link between the risk of cardiovascular disease and the onset of earlier cognitive decline (See Section 4 for the link between cognitive ability and dementia).

Inevitability is also thrown into question by evidence that cognitive decline can be reduced or remediated by teaching interventions. As part of the Seattle Longitudinal
Study, after five hours of individual focused teaching, improved performance was recorded on Spatial Orientation and Inductive Reasoning. Even more interesting was the fact that this result held both for subjects who were found to have declined and those who had not (Willis & Schaie, 1986 cited in Warner-Schaie, 1996). Baltes and Willis (1982 cited in Warner-Schaie, 1996) similarly found group teaching increased performance in older adults (over 60) on tests of Figural relations and Induction. These results have been replicated (Warner-Schaie, 1996). Not only can teaching older adults improve their performance on specific cognitive skills whether decline is in evidence or not, but there is evidence that such teaching has effects on the future trajectory of decline in individuals. Both of the studies mentioned above, included seven-year follow-ups which found that decline was reduced in taught individuals compared to controls, and indicate that individuals who had declined initially, may have benefited most from the training intervention (Willis & Nesselroade, 1990; Willis & Schaie, 1994; cited in Warner-Schaie, 1996). However, the gains were specific to the constructs taught and there was little evidence of any generalisation (Woods, 1996).

7) Summary and Conclusions:
As discussed, research into physical health, mental health, dementia and cognitive performance, despite methodological difficulties, allows us to draw some conclusions as to the inevitability (or not) of age related decline in these areas.

Physical health and illness were discussed in (Section 4). Medical literature contains overwhelming evidence that mortality (the proportion of a sample dying at a specific age) increases with age. Medical evidence also indicates declines in most of the body’s physiological systems. Some of these age related declines result in physical and sensory declines and also in a reduced ability to withstand disease.

However, these changes are widely variable between individuals and modifiable risk factors are still operational in older adults, indicating that they are able to impact on the trajectory of their physical ageing. The occurrence of dementia is robustly found to increase with age, but remains below 10% until the age of 85 years and hence can not be considered to be an inevitable part of ageing.
With regard to mental health (Section 5) large scale studies from the U.S.A. suggest that the proportion of older adults fitting the criteria of a mental health condition is broadly in line with the estimated proportion of younger adults who suffer similarly (approximately 20%). Symptom studies indicate that depressive and anxious symptoms increase in middle to older age despite there being no increase in clinical disorder prevalence with age. There is some evidence that the occurrence of depressive symptoms co-varies with age and sex. There is also evidence that most of the cases of both depression and anxiety found in samples of older adults had an onset in earlier life and hence can not be attributed directly to age changes. Schizophrenia, similarly presents differently in old age and so some caution should be exercised when considering this area. Other difficulties highlighted are the lack of appropriately standardised diagnostic checklists for older adults and the difficulty in differentiating old age onset disorders from those with an earlier onset. Together these results suggest that increasing mental health problems are not an inevitable or universal part of the ageing process except perhaps in those with mental health difficulties in earlier adult life.

With regard to cognitive performance (Section 6), there is good evidence that some decline is likely in the majority of people by their 60s, with serious decline only effecting the majority of those in their late 80s. This decline is likely not to be uniform across individuals, or across cognitive skills in any one person. Furthermore, both risk and protective factors for decline have been identified and there is evidence that steps can be taken by people as they age to minimise the secondary consequences of personal cognitive declines. The utility of teaching interventions on immediate performance and post-teaching decline suggests that older adults may benefit from continued exposure to, or intervention into a range of cognitive challenges and tasks, such as those underpinning a rich and active daily life.

Bringing all these areas together, it can be seen that the description of age related decline as being inevitable, is not reflected by the current evidence. While in most areas most adults will experience some declines these are not universal, do not effect all skills equally, some can be addressed by interventions and compensation is possible in others. Furthermore, mental illness and dementia can be seen not to be inevitable.
parts of the ageing process, effecting as they do less than 25% and 10% of the population respectively until very old age.
References:


To what extent is the cognitive-behavioural approach to pain and its management relevant to children undergoing painful medical procedures?

June 2001

Year 2
To what extent is the cognitive-behavioural approach to pain and its management relevant to children undergoing painful medical procedures?

1) Essay Structure:
The following section (Section 2) serves as a general introduction to the field of pain and its management. Section 3 discusses the theoretical and practical dimensions of and distinctions within, the field of paediatric pain. This is followed by a brief summary of evidence for the effectiveness of cognitive-behavioural pain management interventions with adults (Section 4). Following this, a contemporary model of paediatric pain is discussed (Section 5). Evidence for the clinical effectiveness of child specific interventions is discussed in Section 6. A summary and conclusion section ends the essay (Section 7).

2) Introduction to Pain and Cognitive-behavioural Pain Management:
Children may undergo medical procedures for a wide variety of childhood illnesses or for diagnostic reasons. High rates of anxiety have been found in children before surgery, and children ages 2-6years seem especially at risk, which may lead to lack of co-operation with treatment (Vetter, 1993 cited in Palermo, Drotar & Tripi, 1999) in addition to impairment in social functioning and personal well being (Liossi, 1999). Children with some diseases such as leukaemia, juvenile arthritis and sickle cell disease may have to endure repeated invasive procedures in addition to their disease related pain experiences (Roberts, 1995). Children with cancer report procedures to be the most difficult part of their illness, and repeated exposure has not been found to desensitise them (Liossi, 1999). Even children who are physically well are likely to experience anxiety and pain related to routine dental treatments and inoculations. Finding treatments which can benefit these different groups and that can be conducted within existing services in an appropriate time frame is therefore an important venture. Paediatric procedure related pain (see section 3) has received attention in western medical settings for the past twenty years, though it has been only recently that studies into treatment effectiveness have been undertaken with appropriate methodological rigor.
Early models claimed that pain was a simple and direct physiological process based upon the stimulation of nerves and subsequent transmission to the brain. In a move away from this, one of the most influential models of pain was the Gate-Control Theory of Pain (Melzack & Wall, 1965 cited in Sarafino, 1990). This model was based upon a new understanding of the interconnectedness and mutual influence of neurons within the nervous system. The inhibitory and dis-inhibitory effects of ascending and descending neurons on one another allowed this theory to explain previously puzzling phenomena such as phantom limb pain (pain experienced after a limb is amputated) and neuralgic and causalgic pain (pain with no apparent tissue stimulation). The model posits that the interconnected neurons could act as gates to either open (and hence transmit) or close, (preventing transmission) of pain signals to the brain (Sarafino, 1990). Using this model it was also possible to explain how psychological states such as anxiety, boredom, concentration and relaxation could influence the gating mechanism (Turk, Michenbaum & Genest, 1983).

The importance of psychological factors in the experience of pain has been absorbed into medical and psychological theory, as demonstrated by the fact that The International Association for the Study of Pain defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." (I.A.S.P., 1995 cited in Carraretto, 2001). This contemporary definition states clearly the involvement of emotion and hence psychological factors, in the experience of pain.

One of the most influential trends in modern clinical psychology is that of the cognitive-behavioural approach. This approach has its roots in the empirically derived techniques for behaviour change which fall within the behavioural therapy tradition, including classical conditioning, operant conditioning and modelled learning (Ronen, 1997). Cognitive therapy is based on the idea that a person's thoughts, images, perceptions and cognitive structures largely affect their behaviour (Ronen, 1997) and that one can therefore usefully intervene by making change at this cognitive level. Cognitive-behavioural approaches attempt to keep the proven efficacy of behavioural techniques and to harness the client's cognitive activity for the means of therapeutic change (Kendall, 1991). Whereas in adults, much focus is placed upon the rational
modification of thoughts (negative automatic thoughts and dysfunctional beliefs), cognitive-behavioural interventions with children focus more upon teaching skills such as self-instruction, relaxation and the use of distracting imagery (Ronen, 1997).

The most commonly used cognitive-behavioural intervention techniques for pain management are discussed below. With modification, most if these techniques have been applied to both children and adults. It will be seen however (in Section 6), how often these techniques overlap in clinical practice and in the researched interventions.

**Behavioural distraction:** Most commonly this technique is practised by nurses and professionals taking blood samples, or in the USA by ‘child life specialists’ (a grade of trained staff who are involved in dealing with difficulties during paediatric admissions). It involves distracting the child by the use of attractive stimuli such as soap-bubble blowers, books or toys (Smalley, 1999). This is commonly used with young children (<6yrs).

**Provision of Information and Modelling:** This technique is based on the premise that an unexpected stressor (an event or sensation) and one that is not understood, will be more anxiety provoking than an expected and understood stressor. Information is given to the child about the procedure and the reason for it (procedural information) or the sensations they will experience (sensory information) prior to commencement. A mixture of procedural and sensory information has been found to be most effective in preparing children for medical procedures (Liossi, 1999). Films of children with whom the current child is likely to identify, have been used to give information as above, and also for the purpose of modelling coping behaviours. “Coping models” who show some pain and coping attempts on film, have been found to be more effective than “mastery models” who show not distress at all.

**Use of Imagery and Attentional focus:** Imagery can be used as an adjunct to achieving a state of relaxation, such as where the child is taught how to imagine a favourite holiday scene whilst using a relaxing breathing technique. Alternatively imagery may be used as a means of harnessing the child’s imagination as a means of coping, such as when a child is asked to think about what a favourite super-hero character might do to
cope, or to imagine that they have a special or magical instrument to help them to cope (Langley, 1999).

Relaxation and breathing: Simple slow and deep breathing techniques are commonly used as a short relaxation intervention with children. More elaborate programs use progressive relaxation techniques (tensing and relaxing of muscle groups in sequence) taught prior to admission or before the procedure, which the child is prompted to perform during the procedure (Horne, Vatmanidis & Careri, 1994).

Positive Self Talk: This technique involves teaching children positive phrases such as “I can take this”, “I’m brave enough to stay still” which the child is then asked to repeat to themselves during the procedure. The technique can be understood as enhancing perceived self efficacy, or in terms of being incompatible with catastrophising and negative self statements. Reducing negative self statements is also mentioned as a component in some interventions with late school aged children and adolescents. This cognitive therapy technique requires the assessment of what self statements are spontaneously made, in order that more positive self statements can be learned to replace them.

3) Paediatric Pain, Definitions and Distinctions:
“Pain in children represents a complex cognitive-developmental phenomenon, involving a number of biobehavioural components that interact to produce differential levels of pain perception and verbal and non-verbal manifestations” (Varni, Walco & Katz, 1989). One crucial component of this complex phenomenon rests on the changing developmental level of the child both in cognitive and in behavioural terms. Developmental level has huge implications for the child’s conceptualisation of pain, their experience of distress and their subsequent possibilities for coping with it (Saile, Burgmeier & Schmidt, 1989). There is evidence of marked changes in the spontaneous coping strategies used by children of different developmental ages (Branson & Craig, 1988) which will be discussed below. Children also describe their pain experiences differently as they become more cognitively sophisticated (Branson & Craig, 1993). These intrapersonal differences together with the different relationships to outside influences (e.g. parental reinforcement for children contrasted with social
support for adults) mean that pain in children can not be adequately understood by simply applying what is known of pain in adults (Kendall, 1991).

Paediatric pain can occur in many forms and has been usefully divided into four categories related to its etiology: (1) pain associated with disease states (e.g. vaso-occlusive pain in sickle cell disease); (2) pain associated with observable physical injury (e.g. burns); (3) pain not associated with a specific disease state or injury (e.g. headache); (4) pain associated with medical procedures (e.g. lumbar puncture) (Varni, 1983). This essay focuses on (4) “procedural pain”.

Paediatric pain has also been divided into the following categories based upon its function and time-course; acute pain, chronic pain and recurrent pain. These types of pain serve different functions for the individual and therefore must be assessed and addressed in theoretically and practically distinct ways (Varni, Walco & Katz, 1989). “Acute pain serves as an adaptive biological warning signal, directing attention to an injured part or disease condition, functioning within an avoidance paradigm to encourage escape or avoidance of harmful stimuli and indicating the need for rest or treatment of the injured area.” (Varni, Walco & Katz, 1989). This essay focuses on the acute pain resulting from medical procedures.

“It is often the severe intensity of acute pain and its associated anxiety reaction that most parsimoniously differentiates acute and chronic pain expression. Particularly during painful medical procedures, the anxiety component must be taken into consideration.” (Varni, Walco & Katz, 1989). The fundamental overlapping of pain and anxiety in paediatric procedural pain and the importance of the meaning of the pain experience for the individual are major themes throughout the cognitive-behavioural pain management literature and this essay.

4) Cognitive-behavioural Pain Management in Adults:
Cognitive-behavioural approaches to pain management in adults have been widely researched in the western world over the past twenty years and there is substantial evidence for their effectiveness. The Division of Clinical Psychology’s Occasional Paper No2 (Saxby & Svanberg, 1995) summarised the adult cognitive-behavioural
preparation for surgery literature by saying that “the accumulated evidence shows that there is a relationship between pre-operative psychological distress and post-operative recovery, and that intervention to prepare patients for surgery has beneficial effects. Intervention is most effective when it provides the patient with information about the procedure and the sensations that will result, in addition to behavioural instructions about how to cope and minimise discomfort. The greatest benefit of cognitive coping strategies appears to be in the control and perception of pain.” (British Psychological Society, 1995).

Commensurate with the interest in the effectiveness of clinical interventions, researchers have attempted to test specific hypotheses from compatible models of the pain process. For instance, Pick, Pearce and Legg (1990) found a strong correlation between adults’ spontaneous cognitive coping responses and their reported pain experiences in a medical setting, thus adding theoretical weight to the interest in cognitive interventions for pain management in adults.

This essay does not look any further at the adult pain management literature, as the interest in paediatric pain research which began in the 1980’s has produced a significant body of research dedicated purely to the management of pain in children. So, despite evidence for the effectiveness of cognitive-behavioural pain management in adults, and because as noted previously there are practical and theoretical rationales for not applying adult models and interventions to the management of pain in children, we must look solely at paediatric interventions from here on.

5) A Framework for Paediatric Pain:
The Biobehavioural model of paediatric pain (Varni, 1989 cited in Roberts, 1995) has been influential in the development of western approaches to pain management in children and will serve here to organise discussion of the relevance of cognitive-behavioural approaches to paediatric procedural pain. This section attempts to explore how evidence for some hypotheses based on the model, gives a rationale for providing cognitive-behavioural interventions for children undergoing painful medical procedures.
This broad model hypothesises that a number of biological, cognitive and social intervening variables effect the experience of paediatric pain. The model is based on research identifying risk and resilience factors in paediatric pain (Roberts, 1995). Intervening variables in this model include the critical variable of cognitive development (within biological predispositions) which will impact upon the other intervening variables such as cognitive appraisal, coping strategies as described in Section 3. Many variables held to be important within this model are considered to be potentially modifiable within a cognitive-behavioural approach. The evidence base supporting aspects and hypotheses from within this model can therefore be seen to be a rationale for designing cognitive-behavioural interventions for children in pain.

The importance of developmental level on the spontaneous coping strategies used by children in acute pain has been studied by Brown, O’Keefe, Sanders and Baker (1986) cited in Branson and Craig (1988) in imagined situations. They found that positive self talk was the most commonly reported cognitive coping strategy although only 39.7% of 8-9-year olds reported that they would use this, leaving room for interventions aimed at the remaining children. Attention-diversion and relaxation were reported less frequently, especially in younger children, again leaving room for interventions to
target these strategies in younger children. Brown et al. (1986) also looked at the occurrence of “catastrophizing” (unhelpful cognitions which are challenged or replaced as a crucial part of cognitive interventions). They found that more than 80% of children across the age range 8-18 years reported focusing on negative affect or pain, 25% reported thoughts of escape and avoidance, with other forms of catastrophizing being reported less frequently. This adds weight to the rationale for using cognitive-behavioural interventions with children, as long as they are individually tailored to address the individual’s cognitive and coping needs, their strengths and preferences.

This evidence is for imagined situations and therefore the data may be subject to forms of response bias. However, some studies have looked directly at children’s coping strategies in real life settings. Curry and Russ (1985) cited in Branson and Craig (1988) found that age was positively correlated with the number of coping strategies used and the variety of strategies employed in dealing with dental procedural pain. Branson and Craig (1988) found that their 8-10 year old group of children undergoing painful physiotherapy showed a shift from the behavioural strategies shown by younger children (holding hands etc.) to supplementing these with cognitive strategies (holding hands together with positive self-talk or self-distraction). This is an interesting finding with implications for the tailoring of interventions with different age groups.

Jay, Ozolins, Elliott and Caldwell (1983, cited in Liossi, 1999) found that there was a marked decrease in distress in response to medical procedures at the age of six to seven years of age which they attributed to the increase at this age in the ability to intellectually understand the reason for the procedure and also in the understanding that short term distress would lead to long term benefits.

These two previous findings can be argued to correspond with the change toward formal operational thinking from concrete operational thinking and an increasing ability to decentre (Piaget, 1950 cited in Donaldson, 1978) from developmental psychology. Whereas a concrete thinking younger child might use a behavioural strategy that has helped in a similar setting before and focus only on avoiding the short term pain which may be held to be an attack, the more decentered and formal operational thinking child might add to this with attempts at cognitive strategies which have not been tried in this
setting before, and be more able to consider the longer term consequences of avoiding a procedure now understood to be a doctor’s attempt to help.

So, evidence exists for the use of and changes in, both behavioural and cognitive coping strategies employed by children, giving a rationale for addressing these by cognitive-behavioural means. However, is there evidence that the cognitive coping strategies which are found to be helpful in adults actually are helpful in children?, or conversely that the ineffective coping strategies in adults are so in children? Without this evidence we might teach children developmentally inappropriate or otherwise unhelpful coping strategies.

Much of this particular area of research has focused on chronic paediatric pain populations, as ineffective coping is more adequately defined through interference in activities of daily living or school attendance across time, than through immediate or short term post-procedure measures. However it is reasonable to generalise from chronic paediatric pain populations to acute pain populations where the coping strategies examined are largely aimed at dealing with repeated acute episodes of pain. Good evidence does exist for the link between catastrophizing and less effective coping (and verbal pain expression) during repeated painful physiotherapy procedures (Branson & Craig, 1988). Evidence from chronic populations has also been found by Dunn-Geier, McGrath, Rourke, Latter and D’Astous (1985) cited in Branson and Craig, (1988) in a study showing that “non-copers” defined by effects on their activities of daily living showed more off-task behaviour (non-compliance), more verbal pain expression and more negative behaviour (anger, refusal) than “copers”. This shows that, as predicted by a cognitive model, strategies such as avoidance and catastrophising (a likely part of non-compliance, refusal and anger) would not be effective coping strategies.

A more recent study by Bennett-Branson and Craig (1993) which looked directly at coping in children undergoing acute procedural pain showed that in addition to the above findings, the specific coping strategies used, level of self-efficacy and frequency of catastrophizing cognitions were predictive of post-operative pain, distress and recovery in children 7-16 years of age undergoing surgery. So as in adults, those
children with higher self-efficacy cope better, those with fewer catastrophising cognitions fair better and those using strategies such as self distraction, imagery, positive self-talk and relaxation are also likely to fair better when in pain.

Evidence for the importance of further "biological predispositions" other than developmental level or age, can be illustrated by recent research linking pain sensitive temperament with procedural distress and response to a cognitive-behavioural intervention. Chen, Craske, Katz, Schwartz and Zeltzer (2000) studied fifty-five children undergoing repeated lumbar punctures for the treatment of cancer (an often studied population in the literature). They found that high levels of pain sensitivity were linked with higher anxiety and reported pain before and during the procedures. It was also found that highly pain sensitive children who did not receive the intervention showed the greatest increase in distress over time, whereas highly pain sensitive children who received the intervention showed a decrease in distress.

So it appears that there is paediatric evidence consistent with findings from adult cognitive research which links ineffective coping in medical populations and certain types of cognitive and behavioural activity (such as catastrophizing and avoidance), and more effective coping with other types of cognitive and behavioural coping behaviour (e.g., self talk, distraction). The goal of cognitive-behavioural interventions for children undergoing painful medical procedures therefore becomes increasing positive behavioural coping efforts (relaxing, staying still) and positive cognitive coping efforts (self-distracting, using imagery) together with decreasing unhelpful behavioural coping attempts (crying, squirming) and unhelpful cognitive coping efforts (negative self statements).

6) Implementation and Clinical Effectiveness of Cognitive-Behavioural Paediatric Procedural Pain Management:

Ellis and Spanos (1994) and also Rape and Bush (1994 cited in Boyer, 1998) have recently conducted critical reviews of the effectiveness of cognitive-behavioural interventions for paediatric procedural pain and found substantial evidence to support their effectiveness. However, there are difficulties in establishing efficacy for specific intervention components from the literature as it stands. Difficulties include poorly
described procedures, lack of methodological rigor (blind trials, randomisation and appropriate control groups), failure to measure or balance other intervening variables (age, spontaneous coping, family factors), confusions as to the definition of cognitive-behavioural interventions (hypnosis is often included, see below) and the lack of content analytical studies to tease apart the efficacy of multi-component interventions (Boyer, 1998; Palermo, Drotar & Tripi, 1999).

This section looks at interventions which have a cognitive-behavioural approach underlying them. However, in some cases the researchers are unclear in describing the origins and theoretical base of the intervention which they describe. Stress Inoculation Training has been used as an intervention technology in some studies, based in models such as Schacter’s cognitive model of stress (Jaremko, 1979 cited in Maag & Kotlash, 1994). It contains both cognitive and behavioural components and for the purposes of this essay is not distinguished from other cognitive-behavioural programs. This essay does not discuss clinical hypnotic interventions as they are based on a wholly different theoretical base than cognitive-behavioural interventions. Although they can seem on reading to contain similar components to cognitive-behavioural packages (relaxation, use of imagery), and despite clinical evidence for roughly equal clinical effectiveness (Liossi, 1999), they should not be confounded due to their different theoretical bases and hypothesised methods of action.

However as noted in Section 2, the techniques used in cognitive-behavioural interventions are not always clearly defined. For example, information giving procedures also commonly discuss what the patient can do during the procedure, which could be considered to be teaching coping skills. Doll play is commonly used as part of such interventions, which could be seen as either a form of rehearsal, part of a desensitisation procedure, or giving procedural information. This overlapping may be one of the reasons for a lack of content analytic studies and a reliance on multi-component intervention packages.

A multi-component cognitive-behavioural intervention was investigated by a series of studies by Jay and colleagues. The intervention included five parts; a filmed coping model, a trophy reward for meeting the challenge of the procedure, breathing training,
an emotive and distracting imagery technique, and behavioural rehearsal with dolls. In
the preliminary study, five highly anxious children aged three to seven years, reduced
their anxiety ratings by 50% post intervention (Jay, Elliott, Ozolins & Pruitt, 1985
cited in Liossi, 1999). A second study looked at 56 children aged 3-13 years. This
study showed reduced heart-rates and pain ratings for the cognitive-behavioural group
compared to both an attention control group and a group having the tranquilising drug
looked at 83 children aged 3-12 years divided into cognitive-behavioural or cognitive-
behavioural combined with Diazapam conditions. Both groups showed post-
procedure reductions in self-rated pain scores, though the cognitive-behavioural
condition was more effective than the combined psychological and pharmacological

Similar cognitive-behavioural techniques (play preparation, distracting imagery, a
counting task and a breathing technique) were combined with conscious sedation (pain
killing drugs or creams) and tested against conscious sedation alone in 92 children
undergoing bone marrow aspiration or lumbar puncture. Kazak, Penati, Brophy and
Himelstein (1998) found that the combined psychological and pharmacological
intervention was most effective in reducing nurse and parent ratings of the child’s
procedural distress.

Palermo, Drotar and Tripi (1999) in their critical review of twenty studies specifically
looking at interventions for paediatric outpatient surgery summarised in this way,
“Few positive effects were found for any of the psychosocial interventions. However,
only a small number of randomized controlled trials were conducted and many of the
studies using quasi-experimental designs had significant methodological problems that
limited the interpretation of their findings”. However, despite there very narrow focus
and criteria for the inclusion of studies in their review, positive evidence was found for
interventions aimed at developing coping skills, and in reduced preoperative distress
for interventions providing education and modelling of procedures. Many of the
studies included also had very short interventions given just before the surgery, and
there is evidence that repeated and longer interventions are more effective (Saile,
Burgmeier & Schmidt, 1989).
So, evidence exists for the effectiveness of cognitive-behavioural packages aimed at reducing pain and anxiety in children undergoing painful medical procedures. However, from the biobehavioural model (Fig 1) it can be seen that there are other important variables in children’s experience of pain, other than those which are internal to the child such as perceived control, behavioural and cognitive coping strategies and understanding of the procedure. It may be the case that we could more effectively intervene by altering environmental or family variables (see Fig 1).

One of the most important external variables is the role of the parents (or primary caregivers) in the situation, as most children wish to have them present during procedures. Parents are in a position allowing them (knowingly or not) to model coping behaviour or reinforce distress behaviour. When parents exhibit anxious behaviours, use reassurance consequent to their child’s distress behaviour or are critical of their child, their children have been found to be more distressed (Bush, Melamed, Sheras et al., 1986 cited in Liossi, 1999). Conversely if parents use distraction, imagery or relaxation strategies with their children, there is a reduction in the child’s distress (Bush, Melamed, Sheras et al., 1986 cited in Liossi, 1999). In order to examine this aspect of children’s procedural distress, Jay and Elliott (1987) developed a multi-component cognitive-behavioural program for parents. This was similar to the programs directed at children and described above (using filmed models, information, positive self-talk and relaxation). The parental program was found to be effective in reducing parental anxiety, increasing parental positive self-talk and it also increased the likelihood of parents teaching coping strategies to their children during the procedure. However, parents who watched their children’s preparation package (rather than receiving their own) also used coping strategies with their children. So, allowing parents to watch or join in with their children’s procedural preparation package can be seen to be justified in itself.

7) Summary and Conclusions:
Although the biobehavioural model (Fig 1) pulls together findings from previous research such as the importance of family reinforcement style on paediatric procedural pain expression and can encompass the studies discussed above, there is further work
to be completed in testing all its hypotheses. There is also a need to determine the impact of concepts such as self-efficacy on treatment effectiveness, which could then be easily measured for screening purposes in a clinical setting. There is also a need to assess the impact of culture, its relation to parental coping, children’s coping attempts and the subsequent effectiveness of interventions.

In addition to the acute procedural pain and distress which the majority of interventions discussed in this essay have addressed, there is a separate area of study devoted to addressing the issue of procedural phobia. In the majority of cases this occurs in children undergoing routine medical immunisation or dental treatment and is commonly described as a “needle phobia”. Needle phobia is now classified within the DSM-IV diagnostic manual (American Psychiatric Association, 1994). Menke (1981 cited in Smalley, 1999) found that needles were reported as being the most anxiety provoking part of short paediatric hospitalisations. The importance of the family on the expression of needle phobia has been demonstrated, as 80% of patients presenting with a needle phobia had a close relative with a similar phobia and more than half of adult phobic patients could trace the origins of the phobia back to a childhood experience (Ost, 1991 cited in Smalley, 1999). Addressing needle phobia during childhood or preventing its development may be addressed by a cognitive-behavioural approach using similar techniques to the packages described above (distraction, self-talk, relaxation, imagery) Such programs have been found to be effective by some researchers (Roberts, 1995). In addition, conscious sedation using topical pain killing drugs is recommended (Smalley, 1999).

The utility of a cognitive-behavioural approach to paediatric procedural pain may be established in relation to addressing some intervening variables (increasing cognitive coping strategies, decreasing catastrophizing), but there may be other approaches which are better suited to addressing further external variables such as cultural, family, and environmental variables. There has been some interest in involving parents in cognitive-behavioural preparation programs (Jay & Elliott, 1987) but there has been little research on systemic approaches or interventions in this context. Systemic interventions might be helpful in cases where parental support is not available (or forthcoming), where the child’s coping attempts are undermined by the parents or
where parental anxiety can not be addressed due to a resistance to cognitive-behavioural interventions or cultural and religious concerns over the planned medical intervention.

A recent paper by Boyer (1998) puts forward the case for a wider model for the design and implementation of paediatric procedural pain interventions. Boyer's model attempts to standardise the process of developing individualised treatment approaches, without limiting the possible content of those interventions, including the target of the intervention (for example targeting the parents and wider system rather than the child). This idea appears to the author to have significant clinical merit, though it does not speak to research efforts.

A question which remains is whether the cognitive-behavioural approach is wide enough in its scope to fully address the issue of paediatric procedural pain. The likely answer is no. However, until alternative models are tested empirically to establish other variables which are amenable to psychological intervention in a medical procedure setting, then the cognitive-behavioural approach remains an effective and practical approach. With the increasing number and range of health professionals receiving training in cognitive-behavioural techniques, it is likely that these interventions will increasingly become part of comprehensive paediatric health care in the United Kingdom.

In addition to the ideas discussed above, several issues remain to be fully resolved in this area of research. Firstly, research could usefully target interventions for sub-populations such as children high on scales of pain sensitivity (Chen, Craske, Katz et al. 2000). Secondly research could undertake component analysis of multi-component interventions (Yap, 1988) in order to show which components (often shared between different interventions) are effective and look at their methods of action. Thirdly it would be worthwhile to assess the impact of culture and religion, their impact on treatment acceptability and effectiveness, and on the intervening variables described in the biobehavioural model (Section 5) (Craig & Wyckoff, 1987 cited in Branson & Craig, 1988). Finally, recent research has started to look at the cost benefit analysis of some cognitive-behavioural procedural preparation interventions in the U.S.A., but the
author could find none that specifically addressed paediatric interventions in the United Kingdom. Once these points are answered, hopefully this will ensure that effective cognitive-behavioural pain management interventions are actually provided to children undergoing painful medical procedures.
References:


Clinical Dossier:

This section of the portfolio contains summaries of the five case reports undertaken during the three years of training as well as an overview of the clinical experience gained on each of the four core and two specialist placements.

Full versions of the case reports, placement contracts, logbooks, evaluation forms and sample correspondence can be found in Volume II of the Portfolio.

Please note that all names and specific details which could identify individuals, trusts or establishments have been altered throughout to maintain confidentiality.
Adult Mental Health Case Report Summary:

The outpatient treatment of a thirty year old man presenting with obsessive-compulsive disorder.

Referral:
Mr S. aged thirty years, was referred to the Outpatient Psychology Service by his General Practitioner due to distress over obsessive thoughts and compulsive rituals.

Assessment:
Mr S. was assessed over three sessions, using a cognitive behavioural assessment for treatment structure. The Hospital Anxiety and Depression Scale [HADS] (Zigmond & Snaith, 1983) was conducted to provide a baseline assessment measure. The Responsibility Attitude Scale [R.A.S.] and Responsibility Interpretations Questionnaire [R.I.Q.] (The Wellcome Trust Obsessive Disorder Group, Oxford, 1999) were considered as assessment tools, but not applied due to the client’s marked anxiety during the assessment stage.

Main presenting Problems:
The assessment indicated that Mr S. was experiencing intrusive thoughts, a high level of anxiety and distress over these, and transient depressive episodes. Mr S’s difficulties had an apparent origin in ritualistic behaviour in adolescence. Mr. S’s difficulties were interfering with his work and his relationship with his girlfriend on an everyday basis.

Formulation:
Mr. S’s difficulties were consistent with a diagnosis of obsessive-compulsive disorder. The formulation followed from the cognitive model of obsessive-compulsive disorder. Mr. S was experiencing distress over intrusive thoughts and covert compulsive rituals. Inflated responsibility appraisals and catastrophic beliefs about the intrusive thoughts were leading to negative beliefs about the self and secondary depression. A heavily superstitious family and a history of magical thinking in adolescence set the background for the development of these problems.
**Intervention:**

Mr. S was seen for 12 sessions. The intervention was based upon a range of cognitive behavioural strategies including socialisation to the model, 0-100 anxiety ratings, use of the RAI and RIQ questionnaires, imaginal exposure, graded exposure tasks and identification and challenging of safety behaviours.

**Outcome:**

There was a reduction in the HADS scores for anxiety and depression. Anxiety rating was down to 13 (case) from 18 (case) and depression rating was down from 13 (case) to 8 (doubtful case). There was also an increase in Mr. S’s reported feelings of self-efficacy around his obsessive-compulsive symptoms. There was an increase in Mr. S’s willingness to discuss and confront distressing intrusive imagery and an increase in the use of appropriate coping strategies.

**References:**


People with Learning Disabilities Case Report Summary:

The cognitive assessment of a client with a mild learning disability and bipolar affective disorder.

Reason for Referral:
Helen was referred for a cognitive assessment after reports of a deterioration in her everyday functioning over the past two years. There was concern that cognitive deterioration might indicate an organic pathology which could jeopardise Helen’s forthcoming move into a community unit.

Assessment Components:
The assessment consisted of a review of multidisciplinary notes, interviews with staff, and individual discussions with Helen over a period of two months. Instruments used were The Hampshire Assessment of Living with Others [HALO] (Shackleton-Bailey, Pidcock & Hampshire Social Services, 1982), The Wechsler Adult Intelligence Scale [WAIS-IIIUK] (Wechsler, 1997), The Assessment of Cognitive Deterioration in People with Learning Disabilities [ACDPLD] (Oliver & Crayton, 1993), The Coloured Progressive Matrices [CPM] (Raven, Court & Raven, 1995), The Hayling and Brixton Tests (Thames Valley Test Company, 1997) and the Goodenough-Harris Draw-a-Man Task (Goodenough & Harris, 1950). Details of the rationale for the use of each test and the psychometric characteristics of the instruments are given in the main report. Previous results for two WAIS-R assessments were available for comparison. Simple and short tests were carried out first in order to assess whether Helen would be able to complete the WAIS-IIIUK in her current circumstances.

Assessment Results:
The HALO indicated several activity areas where Helen would show care needs. The Draw-a-Man Task gave no evidence of gross motor, visual or perceptual organisation difficulties and indicated a rough age equivalent of 7-8 years. The ACDPLD served as a quick baseline of cognitive skills which could be easily repeated in future. Helen scored on the 10th centile on the CPM giving an age equivalent of 6 1/2 years. Helen’s performance on both the Hayling and Brixton Tests were in the “impaired” range. The
WAIS-III<sup>UK</sup> indicated a Full Scale IQ of 53, Verbal IQ of 55 and Performance IQ of 59 with a small V-P discrepancy and fairly flat subtest profile. Comparison of scores to previous assessments on both the IQ and subtest level, indicated no significant deterioration in cognitive ability over a period of two years.

**Formulation:**
Comparison of cognitive scores to previous assessments did not support a hypothesis that Helen had suffered significant cognitive deterioration over the past two years. The assessment concluded that other factors must be implicated in any observed deterioration in Helen’s functioning. From the individual sessions with Helen, it was hypothesised that Helen’s deteriorating physical health including an increase in severity and frequency of pain, together with anxiety over her mother’s frailty were significant.

**Intervention:**
As this was an assessment referral, intervention was in the form of feeding back the assessment results to the multidisciplinary team and other day-staff working with Helen. In the light of the assessment results, other hypotheses for the observed deterioration in Helen’s functioning were suggested and recommendations for Helen’s future care were made.

**References:**


Child and Family Case Report Summary:

An assessment and short psychodynamic intervention with a nine year old boy referred for “behaviour and emotional problems”.

Referral:
Michael was referred to the CAMHS team by a local paediatrician after concerns were raised by the SENCO at his school. Concerns were centred on Michael’s behaviour in school which included being demanding of attention and oppositional in the classroom. Michael’s educational progress was being effected. The Paediatrician was concerned that Michael might have Attention Deficit Hyperactivity Disorder [ADHD].

Assessment:
The assessment comprised, a family interview, an outpatient interview with Michael, an interview with Michael’s class teacher, a non-participant school observation, completion of the Connors Rating Scales for parents and for teachers (Connors, 1996), and acquisition of a recent Educational Psychology report. The Family Relations Test (Bene & Anthony, 1985) was conducted to access relationships issues and as a tool to start the intervention.

Main Presenting Problems:
Michael was a bright and able boy with a good level of skill in reading, writing and verbal communication, with cognitive ability within the average range. His presentation at school was variable, being either oppositional or demanding of attention. There was very little evidence of impulsivity, hyperactivity or difficulties with directing attention. There was evidence of marked anxiety and distraction in school however. Michael felt there were significant difficulties in the home, and it appeared that Michael’s relationship with his mother was strained.

Formulation:
A multi-systemic ecological framework was used to compose the formulation (Carr, 1999) with particular reference to attachment theory (Karen, 1994) and Kleinian theory (Gomez, 1997). The Connors Rating Scale information, observation and
analysis of records indicated that in the context of his current circumstances and history, Michael did not meet the criteria for ADHD. Michael was considered to be experiencing anxiety in the context of a problematic attachment relationship to his mother, the recent loss of a father figure and a family history of relationship difficulties across the generations. His difficulties had been maintained by beliefs about non-communication and his mother’s denial of her or her children’s distress over the recent loss of her partner from the household. Michael’s experienced feelings of exclusion from the family and criticism, anxiety over his feelings toward his mother and sister (splitting and projection) and was self-critical in response to these.

**Intervention:**
The intervention consisted of eight individual sessions and aimed to help Michael explore his experiences and difficult unexpressed feelings in the context of a non-critical relationship. The intervention also aimed to help Michael explore his relationship with his mother. To this end, to achieve a state of realistic ambivalence, the “depressive position” in Kleinian terms, in place of the problematic “paranoid-schizoid” position which underlay his current anxiety and the splitting of negative feelings onto his younger sister. Therapeutic techniques included Kleinian play therapy, use of stories to explore feelings, empty chair questions and the drawing or making of illustrative objects. Attempts were also made to address through language, Michael’s negative self references. As the therapeutic relationship was a crucial part of the intervention, much thought was paid to establishing a positive, explicit and worked-through ending to the work.

**Outcome:**
No standard measures were taken. Evidence came mostly from changes in the material explored within the intervention. There was evidence of a reduction in the frequency and strength of Michael’s negative self references. There was evidence of a reduction in splitting and projection of negative feelings onto his sister. Michael began to be able to express ambivalence and say when he felt different things about a person at different times, or felt two things at once about a person. There was no evidence of behavioural change at school, except that Michael agreed to visit a Grammar school which he had previously refused to do, on the grounds that it was too far from home.
References:


Older Adults Case Report Summary:

A narrative intervention with a 78 year old gentleman who presented with depression.

Referral:
Mr. Kit was referred to the Clinical Psychology team by the local Psychogeriatrician after a brief admission for a bout of severe depression. The referral mentioned the recent loss of his younger sister to cancer, his own personal ill-health and a loss of confidence. Mr. Kit was now living back at home with his wife but never left the house.

Assessment:
The assessment comprised of two home-based interviews and use of the Geriatric Depression Scale [GDS]. Special attention was paid to any suicidal ideation, planning and opportunity. The assessment aimed to clarify what Mr. Kit’s concerns were, the severity of the difficulties he was having, and whether a psychological intervention might help to address these.

Main Presenting Problems:
Mr. Kit was a 78 year old gentleman with a complex medical history including heart disease, arthritis, prostate dysfunction (possible malignancy) and mobility restrictions. He could walk a short distance at slow speed but became breathless. He had been a serviceman, had served in the second world war, and had experienced traumatic events. Mr. Kit had lost his younger sister in the weeks prior to his admission, and also had lost his daughter several years ago. There were difficult family relationships between him and his eldest daughter of many years standing which continued into the present. Previous investigation indicated that there was no evidence of cognitive decline.

Formulation:
The formulation was based on social constructionist ideas and the tradition of narrative therapy (Denborough and White, 1999). Mr. Kit was a ex-serviceman with a dominant
story of deriving self worth from physical prowess. He had developed personal coping which relied on stoicism, self-reliance and non-communication. Seeking help resulted in lowered self-worth. Due to the nature of his personal coping, Mr. Kit had not worked through the multiple losses of family and friends stretching back to his traumatic war experiences, nor the continuing difficult relationship with his eldest daughter. The recent loss of his sister and the link to his own increasing frailty, had re-awakened his distress over these past losses.

**Intervention:**
The intervention followed the principles of narrative therapy and sought to help Mr. Kit to re-edit his problematic and competing narratives. This approach holds that the basic unit of experience is the personal story and that these stories can be worked with to make them less problematic. Particular attention was paid to the language used in self-description, the traumatic events of the war which were very much a part of the present difficulty and the contrasting of Mr. Kit’s incompatible stories. The intervention sought to enable Mr. Kit to work with and re-edit his stories, to find evidence against his negative appraisals, make positive stories more accessible, reduce the generalisation in negative stories, and construct realistic stories of events which Mr. Kit had not worked through as yet. In addition to the ten individual sessions, a narrative letter was used as a tool toward the end of the intervention (White and Epston, 1990).

**Outcome:**
There were changes evident in Mr Kit’s telling of his personal narratives, which included a reduction in negative self-appraisals, a reduction in the scope of his negative stories and a willingness to discuss traumatic events within a positive self-story. There were behavioural changes which included increasing use of humour, dressing earlier in the day and walking to the local shops daily. Mr. Kit’s score on the GDS (which because of his personal coping style were likely to be underestimates) reduced from 4 to 1.
References:

Specialist Child and Family Case Report Summary:

The Cognitive Assessment of a 10 year old boy with Sickle Cell Disease.

Referral:
Denzel was referred to the Clinical Psychology Service for Children and Families with Sickle Cell Disease by a Paediatrician from a local hospital. Referral concerns were Denzel’s poor school progress, occasional school refusal and bed-wetting.

Assessment Components:
The assessment aimed to engage the family in the specialist service for the short and long-term, to explore Denzel’s cognitive abilities and explore Denzel’s enuresis and school refusal in order to make recommendations for future work. The assessment included the taking of family, medical and educational histories, interviews with Denzel and his family, administration of the Wechsler Intelligence Scale for Children [WISC-IIIUK] (Wechsler, 1992), the Wechsler Objective Reading Dimensions [WORD] (Rust, Golombok and Trickey, 1993), subtests from the neuropsychological battery NEPSY (Korkman & Kemp, 1998) and the Revised Rutter Parent Scale for School Aged Children (Rutter, 1993).

Assessment Results:
Denzel was a physically small, ten year old boy with sickle cell disease (HbSS) of West African decent who had been resident in the U.K. all his life. He attended a mainstream school in a socio-economically deprived inner city borough. Denzel had primary night-time enuresis, had refused to go to school on several occasions in the last term, had poor school progress from first attendance, he had a stable family history and good relationships with his siblings and parents. The family used English as their first language.

The WISC-IIIUK indicated that Denzel’s Full Scale IQ = 59, Verbal IQ = 65 and Performance IQ = 58. His profile contained notable subtest scatter. He had difficulties in verbal comprehension, abstract reasoning, planning and sequencing. Denzel scored at the 19th centile for Spelling, 7th centile for basic Reading and 7th centile for
Comprehension on the WORD attainment test. The NEPSY indicated some further specific neuropsychological deficits.

Interviews revealed that Denzel had experienced teasing at school because of his sickle cell disease and appearance. Interviews and checklists provided information about the history, parameters and current management of his enuresis. The Rutter Scale indicated no difficulties on the Conduct or Hyperactivity / Inattention scales, a higher score on Emotional difficulties reflecting anxiety, and a strong score on the Pro-social scale reflecting his positive social relationships.

**Formulation:**
Denzel had cognitive abilities in the mild learning disability range. These may have been the result of subtle vascular abnormalities related to Sickle cell disease. These had not been addressed in his school placement, and probably overlooked due to his quiet nature and good social skills. Denzel’s school refusal was considered to be based upon the negative social experiences he had had at school, the inappropriately high level of academic challenge with which he was currently faced and the resulting threats to his self esteem (common in children with chronic health conditions). Factors considered to be important in his enuresis were, anxiety over the above difficulties, the unusually deep sleep states common in children with sickle cell disease, coupled with the need to drink large amounts of water though the day to prevent a sickle crisis which had all acted against his family’s attempts at teaching him.

**Intervention:**
Due to time constraints this referral was considered as an assessment referral. The assessment itself, and the feedback from it, acted as an intervention to engage the family in the specialist service. Systemic intervention was also undertaken in the form of professional liaison, report circulation and recommendations based upon the assessment findings.
Outcome:
Despite early concerns about psychological input, the family engaged well in the assessment. Reports to professionals involved in his care, indicating Denzel’s cognitive strengths and weaknesses, together with a request that his school placement to be re-evaluated were circulated. Ideas and goals for future psychological work were discussed with the supervising psychologist.

References:


Core Adult Mental Health Placement Summary:

Placement Details

Dates of Placement: 13/10/1999 to 18/03/2000.

Supervisors: Leo Estall (Outpatient Clinical and Counselling Psychology Service).
Siobhan Woollett (Community Mental Health Team).

NHS Trust: Kingston and District Mental Health NHS Trust.

Bases: Kingston and District Outpatient Clinical and Counselling Psychology Service.
Esher Community Mental Health Team.

Overview of Clinical Experience

Setting
The placement had two parts. Firstly, outpatient clinical work within a clinical and counselling psychology service taking a variety of mostly primary care referrals. This was based in a suburban borough. Secondly, work with clients under the care of a community mental health team. This was within a semi-rural borough.

Models
The major models used within the placement were a cognitive-behavioural framework and a post-Milan systemic therapy framework.

Clinical Experience
Individual assessments and therapy with a range of adult clients. Presentations included obsessive compulsive disorder, generalised anxiety disorder, phobia, depression, anger problems, panic attacks, problematic bereavement and one distal traumatic brain injury. Work was also conducted as part of a reflecting team working within the systemic family therapy framework.

CMHT presentations included severe depression and suicidal ideation, first episode psychosis, extreme anxiety and personality disorder.
Meetings / Observations / Seminars
The placement offered opportunities to observe supervisors in assessment and therapeutic sessions in both primary care and CMHT settings. Weekly CMHT and Outpatient service meetings offered the opportunity to gain a wider perspective of referrals and treatment options. A one day course on risk management was attended, as was a multidisciplinary specialist group meeting on the issue of early onset psychosis, and a joint meeting between the psychotherapy and clinical psychology services.

Service Related Research Project
A piece of service related research was carried out whilst on this placement. The base for the research was the Adult Outpatient service. The title of the research was “Clients’ Views on Psychologists, Outpatient Psychology Services and Therapy”. This was a quantitative study using a waiting-list survey method to access referred clients’ views and assumptions about therapists given only their professional titles. Feedback from the study was used to inform changes to the waiting list procedure and correspondence. The results were presented to the members of the department at a team seminar.
Core People with Learning Disabilities Placement Summary:

Placement Details


Supervisors: Rosemary Armstrong.

NHS Trust: South West London Community NHS Trust.

Base: Farm House, Orchard Hill, Carshalton.

Overview of Clinical Experience

Setting
The placement offered experience with adults with moderate and severe learning disabilities and those with mild learning disabilities and additional mental health needs [dual diagnoses]. The work was based in small residential units on a large learning disability hospital site. There was a specialist short-term unit for people with dual diagnoses. The site also incorporated several day-centres catering for different sub-groups of residents. There was some scope for additional community based work with people who had moved into local community based residential units. There were opportunities to work with a range of different professions involved in different aspects of care.

Models
The major models used on the placement were behavioural models with a focus on environmental and social manipulations. There was also thinking around team functioning drawing on systems models. Work with clients with dual diagnoses and those with mild learning disabilities living in the community, brought in a cognitive-behavioural focus.

Clinical Experience
This included direct and indirect work with clients with a range of learning disabilities of different aetiologies, across the adult life-span and in a number of care settings. Complex cases such as those of people with dual diagnoses and a client with a
personality disorder and learning disability were addressed. The also work included the assessment of cognitive ability, adaptive behaviour and the care environment.

A social skills group was conducted jointly with a day-centre Occupational Therapy team for clients with dual diagnoses. A training presentation on “autism” was delivered to staff of a community unit to address their team learning needs.

There was also an opportunity to have input into a research project run by a Community Mental Health Nurse looking at the appropriateness of providing nurse-led cognitive behavioural therapy for community clients. This required the use of critical evaluation and research methodology skills. Alterations to the assessment and research design were made and pilot assessments carried out.

**Meetings / Observations / Seminars**

Regular psychology department and multidisciplinary “ward round” meetings were attended. Input to multidisciplinary care review meetings for individual clients was required. Confidentiality policy working group meetings were attended. A lecture on learning disability services for deaf clients was attended, and visits to a range of local day services for people with learning disabilities were conducted. Meetings and discussions were also held with a range of professionals working with clients on site, including Music therapists, Drama therapists and Physiotherapists.
Core Child and Family Placement Summary:

**Placement Details**

**Dates of Placement:** 11/10/2000 to 23/03/2001.

**Supervisors:** Lynne Benjamin.

**NHS Trust:** Invicta Community Care NHS Trust, Kent.

**Base:** Maidstone Child and Family Mental Health Service. Maidstone Child Development Centre.

**Overview of Clinical Experience**

**Setting**

The placement was based in a multidisciplinary CAMHS team servicing a mixed rural and urban borough. There was also substantial input to a child development centre which included nursery provision for children with developmental delays up to four years of age.

**Models**

Systemic, psychodynamic, cognitive-behavioural and developmental models were used throughout the placement.

**Clinical Experience**

The placement offered a range of experience of direct and observed work with children aged up to fourteen years and their families, within the setting of a multidisciplinary CAMHS team. Presentations included impulsivity, hyperactivity, behavioural management difficulties, aggression and risk taking behaviour. There was the opportunity to carry out psychometric assessments and to use some projective tests in therapeutic work.

A group for parents who experienced difficulties with behavioural management of their children was run based on Webster-Stratton’s ideas. The group was planned, run and evaluated jointly with a Community Psychiatric Nurse.
Work in the Child Development Centre involved working closely with a multidisciplinary team (Nursery workers and a Physiotherapist) during a period of change and stress and with children with complex needs. This work involved some informal teaching on psychological models and approaches and helping the team deal with the stress emerging from child protection concerns over one of the children at the nursery.

Meetings / Observations / Seminars
Meetings attended included multidisciplinary “Maidstone Assessment Team for Children” meetings and social services planning meetings for a child on the Child Protection Register. Psychology seminars looking at theoretical matters were attended. A training session run jointly with another trainee was planned and carried out, looking at psychodynamic ideas and exploring how they could be used by the staff team of an adolescent inpatient unit.
Core Older Adults Placement Summary:

Placement Details

Dates of Placement: 17/10/2001 to 22/03/2002.

Supervisors: Catherine Dooley.

NHS Trust: South West London and St. George’s NHS Trust.

Bases: CMHT for Older Adults, Barnes Hospital. The Brysson-Whyte Rehabilitation Unit, Queen Mary’s Hospital, Roehampton.

Overview of Clinical Experience

Setting

Work with older adult clients (65 to 95 years of age) on inpatient assessment wards linked to a Community Mental Health Team for Older Adults. Work with CMHT clients in the community. Additional sessions taking referrals from within an older adults’ physical rehabilitation ward of a general hospital and the inpatient wards there.

Models

Cognitive-behavioural, systemic and narrative models were used throughout the placement.

Clinical Experience

Direct work with older adult clients aged 65 to 95 years of age, across inpatient, outpatient and community settings. Clinical work included cognitive-behavioural and narrative therapeutic interventions. Presentations included depression, anger problems, bereavement and loss, cognitive deterioration, memory problems and relationship difficulties. There was also the opportunity to conduct psychometric assessment with older adults.

Work on the rehabilitation ward involved time-limited assessment and short therapeutic work (maximum 4-6 sessions) with clients presenting with a range of needs whilst undergoing a physical rehabilitation program following surgery, stroke or falls.
Presentations included depression, generalised and health anxiety, phobic anxiety and most cases featured adjustment to physical or lifestyle limitations, or to disability. An inpatient case involved a gentleman presenting with severe depression following stroke.

Additionally a piece of work was begun, to look at the effects of an inpatient ward environment and it’s current signage, on frail elderly people with dementia.

Meetings / Observations / Seminars
Regular attendance at local older adult speciality psychology meetings. This included a presentation to the group (psychologists ranging from Assistants to Heads of Services) on the learning experiences gained through the work on the rehabilitation ward, and thinking around psychological and service models which sprang from those experiences.

Regular attendance at multidisciplinary care planning meetings for the inpatient and community teams was required, as were team meetings on the rehabilitation ward. There was also the opportunity to attend a PSIGE (special interest group) meeting looking at the new National Service Framework for Older Adult services, and discussing its implementation.
Specialist Child Placement 1 Summary:

Clinical Psychology Service for Children and Families with Sickle Cell Disease

Placement Details


Supervisors: Sarah Helps and Sue Bodger.

NHS Trust: South London and the Maudsley NHS Trust.

Bases: The Clinical Psychology Service for Children and Families with Sickle Cell Disease, based at the Mary Sheridan Centre for Child Health, Lambeth. Paediatric Liaison Service, Black Prince Road, Lambeth.

Overview of Clinical Experience

Setting
A split placement in a specialist clinical psychology service for children and families with sickle cell disease and thalassaemia, and within a tertiary paediatric liaison team in a socio-economically deprived urban borough.

Models
Sickle cell service work was based on systemic (including narrative) and cognitive-behavioural frameworks with a focus on models of pain and on chronic health literature. There was also assessment work within a neuropsychological framework. Paediatric liaison work drew on the systemic family therapy framework.

Clinical Experience
Direct individual work with children aged 0 to 14 years and their families coping with sickle cell disease. There was also cognitive assessment work as part of a multi-component assessment of children with sickle cell disease. Additional input was given to a paediatric outpatient clinic, which included children seen by the specialist psychology service.
Paediatric liaison work included direct individual work with children presenting with long-term enuresis or encopresis and their families. This also included work as part of a multidisciplinary systemic family therapy team, working with children with enuresis / encopresis and their families.

**Meetings / Observations / Seminars**

Attendance at regular child psychology department meetings was expected. These meetings included seminars and discussions of psychometric assessment tools, and service provision / developments across CAMHS.

There was the opportunity to attend a training event for SENCO's and teachers, on the impact of and best practice for the management of sickle cell disease and thalassaemia in school-aged children. There was also the opportunity to attend a one-day London-wide multidisciplinary conference on sickle cell disease management approaches. Attendance at monthly child neuropsychology special interest group meetings was also part of the placement. There was the opportunity to shadow Community Nurse Specialists in Haemoglobinopathies to gain a perspective of services for adults with sickle cell disease.

Joint work on a health promotion day at a local secondary school took place. This aimed to promote the issues around sickle cell disease and other chronic childhood conditions and to raise awareness of local health services for children and families with these disorders.

There was also the opportunity to attend the two-day International Narrative Therapy Conference at the Institute of Psychiatry.
Specialist Child and Family 2 Placement Summary:

Child Mental Health Learning Disability Team

Placement Details


Supervisors: Maria Callias.

NHS Trust: South West London and St. George’s NHS Trust.

Bases: Child Mental Health Learning Disability Service.

CAMHS Clinical Psychology Service.

Overview of Clinical Experience

Setting

A Child Mental Health Learning Disability Service. This was a tertiary service with national and local remits to serve children with learning disabilities and additional mental health needs aged 0 to 14 years of age. There were also some cognitive assessment referrals taken from the CAMHS Clinical Psychology waiting list.

Models

Developmental, systemic, behavioural and neuropsychological models were used within the placement.

Clinical Experience

Direct work with children 0-14 years of age with learning disabilities and their families. Presentations included behavioural management difficulties, school refusal, difficulties learning in school, aggressive behaviour, inappropriate sexual behaviour and social or relationship difficulties. All of these presentations were in the context of children with a range of borderline to severe learning disabilities, many of whom had diagnoses of autism or Asperger’s syndrome.
A large proportion of the work involved cognitive assessment of children with complex presentations including autistic spectrum disorders, learning disabilities and those with traumatic histories or genetic disorders (Fragile X, Smith Megenis Syndrome). Assessments therefore often included liaison with Educational Psychologists, Social Workers, teachers and SENCO’s.

Joint behavioural / systemic work on a complex case (an adolescent with autism, moderate / severe learning disability and congenital blindness) was undertaken with a Speech and Language Therapist. There was the opportunity to observe a Nurse Behaviour Specialist and also Psychiatrists in various assessment and treatment milieu. Work with the staff team of a Social Services respite care unit was also required on one case.

**Meetings / Observations / Seminars**

There was regular attendance at CMHLD team meetings and CAMHS psychology team meetings. A presentation of the trainee’s major research project was given to the CAMHS psychology service as it was relevant material.

There was attendance at social service led network planning meetings for an adolescent on the Child Protection Register with whom individual work was being conducted.

In addition the placement offered the opportunity to observe a Consultant Psychiatrist with expertise in Fragile X and autistic spectrum disorders within an assessment setting.

There was also the opportunity to attend several meetings between local Clinical Psychologists and Educational Psychologists to discuss joint working, service development and theoretical issues.
Research Dossier:

This section contains the research undertaken during training.

Firstly appears the Service Related Research Project, carried out during year 1.

Secondly appears the Literature Review, carried out during year 2.

Finally appears the Major Research Project, conducted during years 2 and 3.
Clients' Views on Psychologists, Outpatient Psychology Services and Therapy.

July 2000
Year 2
Abstract:

Title. Clients' Views on Psychologists, Outpatient Psychology Services and Therapy.

Objective. To discover clients' views on the grades of professional staff in the service (in particular their views on Trainee Clinical Psychologists), their understanding of therapy provision and their satisfaction with information given prior to their first appointment.

Design. Postal questionnaires were sent to pre-assessment clients.

Setting. An Adult Outpatient Psychology and Counselling Service in London.

Participants. Participants had been referred by their general practitioners for psychological therapy or counselling and were not previously known to the service. 19 clients responded, aged 18-65 years.

Outcome Measures. Questionnaire data (Likert scales).

Results. The participants' expectations were generally negative about treatment from Trainee Psychologists. There were misconceptions and uncertainty about status within the profession made on the basis of professional titles. Participants thought that the therapist's personality and therapist-client rapport were critical for therapeutic outcome. They were unsure of what treatment would involve or how long it would take. They wished to have more information whilst on the waiting list.

Conclusions: Many clients are misled by professional titles. Clients' views should be sought before adoption of any new professional titles to ensure that misunderstandings are not created or maintained. The service should look into providing more information about the form and content of treatment and professional structure whilst clients are on the waiting list. The impact of the title "Trainee Clinical Psychologist" should be carefully considered in correspondence especially where this constitutes first contact with a client.
Introduction:
The Adult Outpatient Psychology and Counselling Service in which this project was based consists of numerous grades of staff. They have differing orientations and specialities. The service normally includes Trainee Clinical and Counselling Psychologists. Many professional titles sound similar, and personal observation suggests that many clients are misled by some of these titles. Professional titles come about through debate and historical changes rather than by research. The British Psychological Society carried out no research into clients’ reactions to professional titles before adopting the title “Trainee Clinical Psychologist”. The title was seemingly adopted to ensure that misrepresentation did not occur (GTICP meeting June 1999). Debate over the issue continues within the professional body.

Little is known about waiting-list clients’ knowledge of the meaning of these professional titles or of their expectations of therapy in this particular service context.

The titles by which professionals are known may have an effect on clients’ expectations of therapy. These may effect therapeutic outcome or the client’s attendance for appointments and hence impact on the service’s efficiency. Non-attendance rates have been found to be between 24% and 33% for initial and early sessions of psychotherapy (Keen, Blakey and Peaker 1996) which implies a large cost to such a service. Non-attendance rates for this particular service were estimated from contact recordings to be between 13% and 26% at the time the study was set up.

There is evidence to suggest that whilst the majority of clients are happy to be seen by Trainee Psychologists, there is a significant minority who are unhappy about this within a child and family service setting (Vaughan, Morris and Stein 1999). An aim of the present study is to find out whether similar views are expressed by clients in the adult outpatient setting.

An opt-in procedure has recently been adopted by this service. Some research suggests that opt-in procedures with accompanying information may reduce non-attendance (Keen et al 1996). The service has been attempting to improve the efficiency of its waiting list procedure and so clients’ views and expectations of
psychology services would help to inform any further changes. The secondary aims of the study are to reveal waiting list clients’ views of the current waiting list system and their expectations of therapy.

Adult psychology service users have been shown willing to fill out questionnaires, though these were symptom rather than service oriented (Elcombe and Westbrook 1996). A postal questionnaire was designed to explore waiting list clients’ views on the range of issues discussed above.

**Research Questions:**
The study had three aims.

1: To elicit waiting list clients’ views about treatment by Trainee Psychologists in this setting.
2: To elicit their expectations and prior knowledge of therapy.
3: To explore clients’ views on satisfaction with the information provided to them under the present waiting-list system.

It was expected that a significant proportion of clients would have expectations that were out of line with the reality of the professional structure within psychology and also of therapy provision in this setting.

**Method and Procedure:**

*Design.*
The study was a cross sectional questionnaire design.

*Procedure.*
A questionnaire was sent out along with the standard waiting list letter, to clients who had recently opted-in for an assessment appointment.

*Participants.*
35 clients who opted-in during the period of study (April-July 2000) and had been referred by their general practitioner. All clients were over eighteen and under sixty-five years of age. 19 replied with completed questionnaires in time for analysis.
clients had some knowledge of psychology as a profession (2 through work experience and one through reading). The rest denied previous knowledge. Further demographic and referral data was not collected.

**Measures.**

Questionnaire items were designed by the author (see Appendix). Amendments to 4 items and the cover sheet were made after early discussion with service members.

Item 1 asked for a written response if participants had previous knowledge of psychologists' professional structure. The remaining items were 5 point Likert scales and Yes / No check-boxes. Efforts were made to include neutral, negative and positively worded items.

The questionnaire was edited to be twenty two items long and to fit on three A4 pages. A detachable cover-sheet on the service's headed paper was included. The questionnaires were individually addressed but with the cover-sheet marked as detachable to demonstrate the participants' anonymity. The cover-sheet was designed to give a clear rationale for the study and to explain that responses would in no way affect the care received by the participant. Pre-paid return envelopes were included.

The questionnaire was piloted by five people with no previous knowledge of psychology services. This determined how long it would take to complete, the clarity of the items for people with no 'inside knowledge' and their feelings about having to complete it. Two items were re-worded and the items' order was re-arranged following this.

**Results and Analysis:**

30 questionnaires were sent out. 19 replies were made in time for inclusion in the data analysis. The response rate was 63% which is high compared to estimates for postal questionnaires (Robson 1993).

The results below are divided into the three major subject areas. All tables give exact frequencies and approximate percentages which have been rounded to the nearest
whole figure. Although the sample size was small it was felt that quoting percentages made the results more accessible to the reader.

Results Section 1: Views on Trainee Psychologists:

*Ratings of Seniority by Professional Title:*

<table>
<thead>
<tr>
<th>Frequency and (%)</th>
<th>No (i.e. Trainee less qualified)</th>
<th>Yes (i.e. Trainee more qualified)</th>
<th>Don’t Know (Ambiguous)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chartered Clinical Psychologist</td>
<td>17 (90%)</td>
<td>0 (0%)</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Chartered Counselling Psychologist</td>
<td>16 (85%)</td>
<td>1 (5%)</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Counsellor</td>
<td>10 (53%)</td>
<td>7 (37%)</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Associate Psychologist</td>
<td>15 (79%)</td>
<td>1 (5%)</td>
<td>3 (16%)</td>
</tr>
<tr>
<td>Assistant Psychologist</td>
<td>14 (74%)</td>
<td>3 (16%)</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Graduate Psychologist</td>
<td>14 (74%)</td>
<td>3 (16%)</td>
<td>2 (11%)</td>
</tr>
</tbody>
</table>

Yes / No rating items for the above revealed that the title “Trainee Clinical Psychologist” is thought by the majority of participants (74%) to indicate less qualification than “Graduate” and “Assistant Psychologist”. 79% thought that Trainees were less qualified than the as yet unused title of “Associate Psychologist”. 2 participants did not answer any of the ratings questions.

What is it Acceptable for Trainee Psychologists to do?

<table>
<thead>
<tr>
<th>Frequency and (%)</th>
<th>Acc’ for Trainee to Observe 1st Appt?</th>
<th>Acc’ for Trainee to Conduct 1st Appt?</th>
<th>Acc’ for Trainee to Treat On-going?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>5 (26%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Agree</td>
<td>10 (53%)</td>
<td>6 (32%)</td>
<td>5 (26%)</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>2 (11%)</td>
<td>4 (21%)</td>
<td>7 (37%)</td>
</tr>
<tr>
<td>Disagree</td>
<td>1 (5%)</td>
<td>7 (37%)</td>
<td>5 (26%)</td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>1 (5%)</td>
<td>2 (11%)</td>
<td>2 (11%)</td>
</tr>
</tbody>
</table>

Approximately 79% of participants agreed that a Trainee Psychologist could observe their first appointment with 10% disagreeing. 48% were against a Trainee conducting their first session and 37% were against a Trainee treating them. These data show that
there is unease amongst a significant minority of clients over the issue of treatment by Trainee Psychologists.

*Is Seeing a Trainee Likely to Effect Attendance for an Assessment?*

42% said that they did not know whether being told they would see a Trainee would effect their attendance for an assessment appointment.

One client strongly agreed and one strongly disagreed with the statement. 47% stated that their attendance would not be effected.

*What Would Clients Think if a Trainee was Treating Them?*

<table>
<thead>
<tr>
<th>Frequency and (%)</th>
<th>Yes</th>
<th>Don't Know</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Think they were working within their abilities.</td>
<td>11 (58%)</td>
<td>1 (5%)</td>
<td>7 (37%)</td>
</tr>
<tr>
<td>Think I was getting the best treatment available.</td>
<td>3 (16%)</td>
<td>2 (11%)</td>
<td>14 (74%)</td>
</tr>
<tr>
<td>Think they were not experienced enough.</td>
<td>10 (53%)</td>
<td>2 (11%)</td>
<td>7 (37%)</td>
</tr>
<tr>
<td>Be likely to stop coming to appointments.</td>
<td>6 (32%)</td>
<td>2 (11%)</td>
<td>11 (58%)</td>
</tr>
<tr>
<td>Think I was getting appropriate treatment.</td>
<td>6 (32%)</td>
<td>2 (11%)</td>
<td>11 (58%)</td>
</tr>
<tr>
<td>Ask to see someone else instead.</td>
<td>9 (47%)</td>
<td>2 (11%)</td>
<td>8 (42%)</td>
</tr>
<tr>
<td>Think they were not skilled enough to help me.</td>
<td>9 (47%)</td>
<td>1 (5%)</td>
<td>9 (47%)</td>
</tr>
</tbody>
</table>
On the strongly worded item asking if clients thought that they were “getting the best treatment available” 74% stated that they thought they were not. 58% however, thought that they would be receiving “appropriate treatment”, with 32% thinking they would not be.

A similar proportion (32%) as in the earlier question addressing likelihood of non-attendance, stated that they would be likely to stop coming for treatment by a Trainee.

Participants were roughly evenly divided as to whether they would ask to see someone else (47% would and 42% would not).

Opinion was equally divided (47%) as to whether a Trainee would be “skilled enough to help”, and similar division was stated over whether a Trainee would be “experienced enough to help” (53% thought not, 37% though they would be).

**Who Would Participants Rather be Treated By?**

<table>
<thead>
<tr>
<th>Frequency and (%)</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Don’t Know</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prefer to be Treated by a Chartered Clinical Psychologist.</td>
<td>2 (11%)</td>
<td>6 (32%)</td>
<td>9 (47%)</td>
<td>2 (11%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Prefer to be Treated by an Associate Psychologist.</td>
<td>0 (0%)</td>
<td>1 (5%)</td>
<td>17 (89%)</td>
<td>1 (5%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Prefer to be Treated by an Assistant Psychologist.</td>
<td>1 (5%)</td>
<td>4 (21%)</td>
<td>13 (68%)</td>
<td>1 (5%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

The results show that there is a high level of uncertainty when asked to state which of three professional grade titles they would prefer to be treated by. This may reflect uncertainty about the titles themselves. However uncertainty might also be raised as it may reflect the individual’s thinking about whether grade is necessarily an important factor for outcome (see Results Section 2).

As with the previous grade rating questions (see above) participants who stated a preference say they would prefer to be treated by an Assistant Psychologist rather than a Trainee when given only title information.
Results Section 2: Expectations of Therapy and Service:

Number of Appointments Expected.

The mode response was 6-10 appointments. 26% of participants expected to be seen between 2 and 5 times. 58% of participants expected to be seen less than 11 times. The service operates around an approximate 15 session per-client allocation.

Expected Frequency of Appointments.

The mode response revealed that participants (47%) expected to be seen once a week. 26% thought they would be seen once a month and 21% thought once a fortnight. There was one missing value.
Factors Thought to Effect Therapy Outcome.

<table>
<thead>
<tr>
<th>Frequency and (%)</th>
<th>Skills have a lot to do...</th>
<th>Grade has a lot to do...</th>
<th>Personality has a lot to do...</th>
<th>Getting On has a lot to do...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree or Disagree</td>
<td>1 (5%)</td>
<td>6 (32%)</td>
<td>1 (5%)</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>2 (11%)</td>
<td>6 (32%)</td>
<td>0 (0%)</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Strongly Agree or Agree</td>
<td>16 (84%)</td>
<td>7 (36%)</td>
<td>18 (95%)</td>
<td>15 (79%)</td>
</tr>
</tbody>
</table>

Participants responded that “therapist’s personality” (95%), “therapist’s skills” (84%) and “getting on” (79%), were all important for therapy outcome. Opinion was more equally divided on the issue of “therapist’s grade” with 36% regarding it as important and 32% thinking it was not or stating that they did not know. There were no missing values.

Are Participants Sure of How Long Therapy Will Take?

84% of participants stated that they were unsure of how long treatment would take (24% “agreed strongly”). 5% stated that they were sure they knew. 11% answered that they did not know whether they knew or not.

This suggests that any information given out in future should include information about likely treatment length.
Are Participants Unsure of What Treatment Will Involve?

84% agreed that they felt unsure of what treatment would involve. 1 client stated that they were sure what treatment would involve.

11% answered that they did not know whether they were sure or not.

Results Section 3: Views on Information Given:
Do Clients Expect to Know Therapist Grade before Attendance?

53% of participants thought that they should be told the grade of the therapist before attending their first appointment. 26% did not know and 21% said that they did not expect to know the therapist’s grade at this stage.

At the moment this information is given within a signed letter from the therapist offering an assessment appointment.


**Do Participants Want More Information Prior to Referral?**

26% said that they did wish to have more information about the service before referral by the general practitioner. However, 31% said that they did not want any more information at that stage. 42% did not know whether they wanted more information or not at that stage.

---

**Do Participants Want More Information Whilst on the Waiting List?**

69% of participants said that they like some more information about the service whilst on the waiting list, with 11% feeling strongly about this. 16% said they did not want any more information at this stage, and 16% said that they did not know either way.

It would therefore seem that participants do want to have more information about the service whilst they are waiting for their first appointment.
**Do Participants Feel Satisfied with the Information Given Now?**

Participants who stated an opinion were equal in number on this issue. 37% said that they were satisfied with the information provided under the current waiting list procedure. 37% stated that they were not satisfied. 26% said that they did not know whether they were satisfied or not.

**Other Comparisons.**

Box-plots were obtained and extreme values examined, which showed that one participant stated extreme views across several variables.

Mann-Whitney U tests were run using Previous Knowledge as the grouping variable. Cases were excluded pair-wise. The groups (those with previous knowledge and those without) could not be proven to be separate except on whether “therapist’s personality” effects therapeutic outcome. Those with previous knowledge stated more strongly that personality would effect outcome. Sample size was very small however (Yes group, N=3).

**Discussion:**

The sample taken is likely to be representative of the service’s client group as they were randomly selected, apart from exclusion of Community Mental Health Team (CMHT) referrals. General practitioner referrals constitute the bulk of referrals to the service. CMHT referrals were excluded on the grounds that they may have included long-term service users with much experience of services and more extreme mental health needs. Moreover the sample’s views are likely to be representative of adult clients attending outpatient psychology, counselling and similar primary care based services in other geographical areas.
The questionnaire items included seventeen neutrally worded items and six items which by their nature may have led clients to think Trainee Psychologists were a concern. This should be borne in mind when considering the results of this study.

Clients seem to be misled by some professional titles (Tables 1 and 4). The need for Trainees to fully describe their status within the profession as taught during clinical training is thus highlighted by this data. Adequate time should be left for clients' questions as views and concerns may vary markedly and all participants showed negative views or misunderstandings about Trainees.

Although some individual participants held stronger negative views with regard to trainees than others, the majority expressed several negative views throughout the questionnaire. Thus the results seem to express generally held beliefs rather than extreme views of a small subgroup.

Trainees should be aware of the impact that their professional title may have on the reader of any correspondence, especially if this constitutes first contact with a client such as an assessment appointment letter. A significant minority of participants stated that they would be less likely to attend an appointment with a Trainee (32% Table 3). Fewer stated that they were less likely to attend on a later and more strongly worded item (Figure 1), though in that item 42% were unsure whether they were less likely to attend or not.

The link between stated intentions (being less likely to attend) and actual behaviour has not been addressed in this study. However, non-attendance rates for therapy have been found to be similar to the proportion of participants in this study who stated that they were likely to not attend. Differential non-attendance rates for therapy given by Trainees compared to other grades of staff would be an area worthy of audit.

Reconciling the wishes of clients to know the grade of therapist they are to see with the concerns that this may raise is a difficult issue (Figure 6) which might be addressed with the provision of information (see below).
In the future more attention should be paid by professional bodies to the opinions of service users before professional titles are adopted. The importance of service users' reactions to professional titles has been overlooked in the past, resulting in some widely held misunderstandings with regard to the relative grades of psychology service staff.

From the data gathered here the service might consider looking into providing more information about the form and content of treatment whilst clients are on the waiting list (Figure 8).

Data from the items regarding expectations of treatment length and appointment frequency suggests that any information given out in future should include estimates treatment duration (84% were unsure of duration). Information might also include a description of the therapy process as the majority of participants were unsure of what treatment would involve (Figures 4, 5 and 8).

Literature might also usefully include information about the grade structure of the professions involved, in order that some concerns be addressed before the client attends (or decides not to attend) their first appointment. However, there is an issue of whether this subject should be addressed in person when other factors such as personality and rapport come into play, or by impersonal literature.

The data supports the position that waiting list clients have major areas of uncertainty about the treatment that they are going to receive, and that they would like more information at this stage. By providing some information to waiting list clients, the service might become more transparent and address clients' concerns before they become factors leading to non-attendance.

Procedures for gaining consent to treatment by a Trainee Clinical Psychologist might need to be reviewed in some services, though in this service it is currently quite explicit. A significant proportion (37%) of participants thought treatment by a Trainee would not be appropriate and 48% thought that it was not appropriate for a Trainee to
conduct the assessment appointment (Table 2). These data are broadly in line with the findings of Vaughan, Morris and Stein (1999) gained whilst looking into waiting-list stress in a Child and Family setting.

How clients’ opinions might be effected by a change in the title of pre-registration psychologists undergoing professional training, might constitute the next step in exploring these issues.

The results of this study were fed back to the service through a seminar session in December 2000.
References:


Appendix:

The Questionnaire.

This document was originally printed on the service's headed paper and fitted exactly onto 4 sheets of A4 paper. It has been amended to fit the margins of the Portfolio and thus its formatting has been altered.
This research questionnaire has been sent to you to find out what you think about psychologists and psychology services.

Your answers will be anonymous, confidential and are not seen by psychologists in the Psychology and Counselling Service.

The answers you give will not effect the care that you will receive within the service.

Your answers will be grouped with those of other people on waiting lists and will tell us how the service could be improved for clients like yourself in the future.

There are 22 questions. They will take about 5 minutes to fill in.

Thank you very much for your help.

Please send the completed questionnaire using the pre-paid envelope.
Thank you.
Survey of Waiting List Clients’ Views

1) Have you heard or seen the titles; Assistant Psychologist, Associate Psychologist, Chartered Clinical Psychologist, Chartered Counselling Psychologist, Trainee Clinical Psychologist or Graduate Psychologist before? 
   Yes / No

2) If Yes, which title do you know and where have you seen it?

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

Tick ONE box.

3) I expect to be seen by a psychologist for:
   1 appointment
   2-5 appointments
   6-10 appointments
   11-20 appointments
   More than 20

4) I expect to be seen by a psychologist:
   More than once a week
   Once a week
   Once a fortnight
   Once a month
   Less often than once a month

Please clearly mark the box which best reflects your opinion:

5) The skills of the person I am seen by, have a lot to do with how useful my treatment will be.

   Strongly Disagree  Disagree  Don't Know  Agree  Strongly Agree

6) The grade / seniority of the person I am seen by, has a lot to do with how useful my treatment will be.

   Strongly Disagree  Disagree  Don't Know  Agree  Strongly Agree

7) The personality of the person I am seen by, has a lot to do with how useful my treatment will be.

   Strongly Disagree  Disagree  Don't Know  Agree  Strongly Agree

8) Whether the therapist and I “get on”, has a lot to do with how useful my treatment will be.

   Strongly Disagree  Disagree  Don't Know  Agree  Strongly Agree
Survey of Waiting List Clients' Views

Circle YES/NO for EACH LINE

9) A Trainee Clinical Psychologist is more qualified to treat me than:
   (random list)
   A Chartered Clinical Psychologist   Yes / No
   An Assistant Psychologist          Yes / No
   A Graduate Psychologist            Yes / No
   An Associate Psychologist          Yes / No
   A Chartered Counselling Psychologist Yes / No
   A Counsellor                      Yes / No

Please clearly mark the box which best reflects your opinion:

10) I expect to know the grade of the person I am to see before my appointment.
    
    Strongly Disagree  Disagree  Don't Know  Agree  Strongly Agree

11) I would be less likely to attend an appointment with a Trainee Clinical Psychologist.
    
    Strongly Disagree  Disagree  Don't Know  Agree  Strongly Agree

12) I would be happy for a Trainee Clinical Psychologist to observe my first / “assessment” appointment.
    
    Strongly Disagree  Disagree  Don't Know  Agree  Strongly Agree

13) I would be happy for a Trainee Clinical Psychologist to conduct my first / “assessment” appointment.
    
    Strongly Disagree  Disagree  Don't Know  Agree  Strongly Agree

14) I would be happy to be treated by a Trainee Clinical Psychologist.
    
    Strongly Disagree  Disagree  Don't Know  Agree  Strongly Agree

Circle YES/NO for EACH LINE

15) If I was treated by a Trainee Clinical Psychologist I would:
    Think they were working within their abilities. Yes / No
    Think I was getting the best treatment available. Yes / No
    Think they were not experienced enough. Yes / No
    Be likely to stop coming to appointments. Yes / No
    Think I was getting appropriate treatment. Yes / No
    Ask to see someone else instead. Yes / No
    Think they were not skilled enough to help me. Yes / No
Please clearly mark the box which best reflects your opinion:

16) I am unsure of how long my treatment will take.

17) I am unsure of what my treatment will involve and what I will have to do.

18) I would prefer to have more information about the Psychology and Counselling Service before referral by my GP.

19) I would prefer to have more information about the Psychology and Counselling Service whilst on the waiting list.

20) I would prefer to be treated by a Chartered Clinical Psychologist than a Trainee Clinical Psychologist.

21) I would prefer to be treated by an Assistant Psychologist than a Trainee Clinical Psychologist.

22) I would prefer to be treated by an Associate Psychologist than a Trainee Clinical Psychologist.

Please send back the completed questionnaire using the pre-paid envelope.
Thank you again.
Appendix: Letter from Feedback Seminar
19 February 2001

Mr Andy Gentil
Student
University of Surrey
Guildford  GU2 5XH

Dear Andy,

Thank you very much for your presentation to our department last month. It was very interesting and has stimulated a good deal of thought. Certainly I may like to contact you in the future should other trainees wish to develop this research further.

Thanks again for your time.

Regards

[Signature]

2001
Year 2

A: Introduction:
This review takes stress and coping in fathers of children with autism as its central point of interest. As the research literature on this specific issue is extremely limited at present, the review extends to stress and coping research in both-gender parents of children with autism and other chronic conditions. Much of the review looks at whether autism is a special case in relation to parental stress and at the instruments used to examine the issue. The review then considers if and how mothers and fathers differ with regard to stress and coping. Then bringing these areas together, ideas for future research are considered.
Below, a map is presented of the review’s major themes and the order in which they appear (fig. 1). The parallel issues run throughout the literature and are discussed when appropriate throughout the review.

**Main Themes / Sections**

- Coping and Stress:
  - What are they?
  - How do we study them?
- Differences in Stress and Coping across Diagnosis:
  - Is autism different?
- Mothers and Fathers:
  - Are there gender differences in parental stress and coping?

**Parallel Issues**

- Methodology
- Measures QRS / PSI
- Sampling / Culture
- Wider Context

**Summary and Conclusions:**

Where next?
B: Significance of the Topic:

Autism was first reported by Kanner (1943 cited in Volkmar, 1999), but only appeared as a diagnostic category in the American psychopathology classification system in 1980 (DSM-III, American Psychiatric Association [APA], 1980). The terms 'autistic disorders' and 'pervasive developmental disorders' are "characterised by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behaviour, interests and activities" (APA, 1994, p65).

It has only been in the last decade that substantial consensus has been reached with regard to the diagnosis of autistic disorders. The recent alignment of the European ICD-10 (World Health Organisation, 1993) and American DSM-IV (APA, 1994) diagnostic systems is an indication of this trend (Filipek, Accardo, Baranek, Cook, Dawson, Gordon, Gravel, Johnson, Kallen, Levy, Minshew, Prizant, Rapin, Rogers, Stone, Teplin, Tuchman and Volkmar, 1999). However, there remains debate about exactly how to define childhood autism, related conditions such as Aspergers syndrome, and the 'ends' of what is now thought of as the autistic spectrum (Volkmar, 1999).

Estimates of the prevalence of autistic disorders range from 1 in 2000 in the USA in 1996, to 1 in 500 in the USA in 1999 using the latest diagnostic criteria (Filipek, Accardo, Baranek et al., 1999). To put this into perspective, autistic disorders are more common than childhood cancer, diabetes, spina-bifida, or Down syndrome. There is no known biological marker, or cure for autism. The average male to female ratio has been reported as 3:1 to 4:1. (Filipek, Accardo, Baranek et al., 1999).

Theories about the aetiology of the disorder have changed markedly since 1943, across different countries and research groups. Approaches to autism have moved through a developmental view-point, through seeing it as a form of childhood schizophrenia, through placing parents at the centre of the aetiology, to being concerned with the genetic and inherited characteristics of the disorder. Parents who originally would have been treated as part of the problem, are now regarded as critical agents in the
successful management of the condition. It is with this understanding, that the study of stress and coping in the parents of children with autism has received attention.

The diagnostic process surrounding children with autistic disorders has been found to be a prolonged and stressful experience for parents in many cases (Howlin and Moore, 1997). Parents typically notice that something is wrong with their child by the age of eighteen months (Howlin and Asgharian, 1999). However, diagnosis occurs in the U.K. at a mean age of 5.49 years (Howlin and Asgharian, 1999), and in the USA at a mean age of 4 years (Filipek, Accardo, Baranek, et al, 1999). This commonly results in a long and stressful wait before the family is able to access appropriate supports (Howlin and Moore, 1997).

C: Parental Stress and Coping: An Overview.

This section discusses some of the major shifts and trends within the field, encompassing the literature on both autism and other chronic childhood conditions, as the two are enmeshed. Some of the issues discussed here are returned to in the discussion of specific studies later in the review.

Stress and coping are words which have moved from the behavioural laboratory into everyday western language. Stress is usually considered as being a person’s perception of a threat or challenge, with coping being generally defined as the person’s response to the challenge, or perceived stress (Hymovich and Hagopian, 1992).

Work in the field of parenting stress in autism has evolved along a simple dimension when considered in broad terms. It has moved from an interest in the parents’ impact on the development of the child and their condition, to consideration of the effect of the child on the parents. In the last decade, some researchers have gone on to use a family systems perspective, thus bringing the mutual interaction of effects of both the parents and children together in their analysis (Morgan, 1988). This evolution has accompanied a shift in the understanding of the inherited aetiology of autism and away from ‘parent blame’. The evolution was also closely linked to findings from studies into other chronic childhood conditions (such as Down Syndrome and Cystic Fibrosis;
Another important difference in approach between researchers is whether they consider that stress is best considered and hence measured, as an objective or a subjective phenomenon. The objective position is implicit in some developmental accounts of parenting stress, where researchers looked to find direct links between child behaviours or personality characteristics, and measures of parenting stress such as tranquilliser use and other parent behaviours. Although rarely discussed openly in research, this could be thought of as a behavioural model of stress, with stress being entirely contingent upon the challenge to the parent.

In contrast, the subjective position holds that the link between the challenge and the resulting parental stress are indirect. The individual parent’s stress appraisals are held to mediate between the objectively measurable challenge, and the resultant subjective perceived stress. Again, though rarely discussed specifically in research, this approach seemingly has a cognitive model of stress underlying it (Lazarus and Folkman, 1984 cited in Milgam and Atzil, 1988).

Whilst this evolution of ideas progressed, researchers examined whether all chronic child conditions created similar parental stress (the ‘non-categorical’ view; e.g. Stein and Jessop, 1982), or whether there were predictable differences in parental stress between different physical and psychological conditions (the categorical view; e.g. Boumer and Schweitzer, 1990). Central to the resolution of this debate have been efforts to develop condition-specific, reliable, discriminative and sensitive measurement tools of parenting stress and coping.

D: Parenting Stress and Coping in Autism, same or different across diagnosis?
Findings for a non-categorical approach, i.e. that parental stress and coping is not closely linked the specific diagnosis, or specific difficulties with which the child presents, come firstly from research into defining what aspects of health care provision parents value.
Baine, Rosenbaum and King (1995), conducted a postal survey of 167 parents of children with diabetes mellitus or cystic fibrosis. They found a Spearman’s rank correlation of $r=0.92$, $P<0.001$ between the groups’ responses with regard to the absolute and relative importance of 22 components of care on an instrument they devised. They note that these results also correlate with previous findings from parents of children with neuro-developmental diagnoses ($r=0.72$, $P<0.001$). In an earlier study, Redman-Bentley (1982 cited in Baine, Rosenbaum and King, 1995) examined the issue in parents of children with Down syndrome, Cerebral Palsy, and Developmental delay. They found substantial consistency across these groups of parents’ ratings also. ‘Specific Treatment’, ‘Continuity and Consistency’, ‘Parent Involvement’, ‘Education / Information’, and ‘Accessible care’ were the consistently rated as the most important components of care by parents across the groups.

However, although these authors make a link from their findings to parental stress, there seems to be little rationale for doing so. Although these findings suggest ways that services could better address parental wishes and perceived needs, they provide no evidence that the identified issues were significant stressors for the parents. Nor do they provide evidence that meeting these needs would reduce parental stress, and no measures of parental stress were taken. Another difficulty, was the wide categories employed. ‘Parent Involvement’ for instance, might mean being able to stay with a child who is in hospital for surgery for cystic fibrosis, to being involved in care-planning for parents of children with Down syndrome. Correlations between such blunt measures without controls for other variables are not persuasive. To link these interesting findings on parents perceived needs to parenting stress across a range of diagnostic groups, and then concluding that parenting stress is similar across these groups is inappropriate.

In contrast to this, researchers began to address the categorical / non categorical debate directly. A significant attempt to discover whether parental stress in autism was situation specific or a general gross stress reaction, was by Koegel, Schreibman, O’Neill and Burke, (1983). They found that 49 parents of early school-age autistic children and parents of developmentally normal children scored similarly and within the
normal ranges provided by the instruments, on a standard personality measure (the MMPI, reference not quoted), a measure of marital adjustment (Dyadic Adjustment Scale, Spanier, 1976 cited in Koegel et al 1983), and a measure of family functioning (Family Environment Scales, Moos and Moos, 1981 cited in Koegel et al 1983). They concluded that their results do not support a general stress reaction in parents of children with autism, or higher levels of psychopathology, but that parental stress must be variable and situation specific. This implies that parental stress would be sensitive to the specific challenges presented by different chronic childhood conditions, and other child characteristics.

What was needed to move the research on, was the development of valid and reliable instruments to measure parenting stress. These would need to encompass not just a single construct, but be able to tease apart different aspects of parental stress. There were two noteworthy answers to this need, the Questionnaire on Resources and Stress (Holroyd, 1974) and later, the Parenting Stress Index (Abidin, 1995, originally published 1983). These instruments are described below, followed by examples of research using them to examine parenting stress in autism compared to other diagnostic groups.

The Questionnaire on Resources and Stress [QRS]:
The QRS (Holroyd, 1974) appears to be the most commonly used instrument designed to measure parenting stress and coping in clinical populations. The original version consists of 285 true/false items which look at both the positive and negative impact of the child on the family. There are 15 a priori scales. The QRS has been found to differentiate stress as a function of psychiatric condition (Holroyd and McArthur, 1976), handicap versus no-handicap (Holroyd, Brown, Wikler and Simmons, 1975), and the effect of lone parenting (Holroyd, 1974). Holroyd, (1988) reviewed studies using the 285 item QRS. She concluded that the QRS had been found to discriminate by child characteristics, diagnosis, degree of handicap, parental attitudes, whether a child is institutionalised or not, and by family characteristics. There is evidence of validity from the strong correlations between interviewer ratings of parental stress and maternal scores (Boumer and Schweitzer, 1990).
Freidrich, Greenberg and Crnic, (1983) constructed a shorter version, using the original item pool, retaining items on aspects of physical disability. Holroyd (1982 cited in Salisbury, 1985) made an official short-form using 66 items (QRS-SF). Validity and reliability testing showed some difficulties, (Salisbury, 1985) resulting in a psychometrically stronger version being released (Salisbury, 1986). Boumer and Schweitzer describe the QRS short form thus; “a self-administered questionnaire for parents that contains 66 True/False items and 11 subscales based on statistical factors . . .and clinically derived scales. The 11 factors that it examines are: Dependency and Management; Cognitive Impairments; Limits on Family Opportunities; Life Span Care; Family Disharmony; Lack of Personal Reward; Terminal Illness Stress; Physical Limitations; Financial Stress; Preference for Institutional Care; and Personal Burden for Respondent.” (Boumer and Schweitzer, 1990, p725). Individual scale and overall scores can be derived, and profiles plotted.

A Canadian research group went on to develop an alternative shortened version of the QRS called the Clarke Modification of Holroyd’s QRS. This aimed specifically at severe child psychopathology, by removing items related to physical and medical disabilities, and increasing the range of response from true/false to 4 point scales on critical items. Impressive reliability and validity data is provided in their study (Konstantareas, Homatidis, and Plowright, 1992).

Research using the QRS:
Holroyd and McArthur, (1976) used the long-form (285 item) QRS to compare 76 parents of children with autism, Down syndrome and those attending an outpatient psychiatric clinic. Their findings were that parents of children with autism had the highest level of parental stress as measured by the QRS, with the Down’s group being next, and those with other difficulties again scoring lower. Compared to the other groups, parents of children with autism were more concerned about the dependency of the child, the effects on the rest of the family, and the lack of suitable activities available for the child. These results clearly demonstrate inter-group differences in stress and coping and hence evidence for a categorical view.
Holroyd and Guthrie, (1986) used the ‘Questionnaire on Resources and Stress’ short-form (Holroyd, 1982 cited in Salisbury 1985) with parents of children with cystic fibrosis, neuromuscular diagnoses and an age and socio-economic status matched control group. They found that parental stress differed in its pattern across the scales of the instrument depending on diagnosis, and the amount of care the child required. Parents of children with cystic fibrosis scored higher for stress associated with the scales ‘financial stress’, ‘insufficient social support’, ‘life-span care’, and ‘physical incapacity’. Parents of children with neuromuscular diagnoses scored higher on more and different scales in keeping with the demands consequent on their child’s condition. Although, not directly relevant to autism, these findings indicate that parental stress profiles do differ (at least indirectly) as a function of the child’s disorder, and that the QRS has again been able to discriminate between such groups.

Bouma and Schweitzer, (1990) compared 24 mothers of children with autism, 24 mothers of children with cystic fibrosis, and 24 mothers of asymptomatic children using the 66-item ‘Questionnaire on Resources and Stress, short form’ (Holroyd and Guthrie, 1986). They found that “each clinical group exhibited different patterns of stressful response consistent with the nature of the disorder and the requirements of care imposed on the family” (Bouma and Schweitzer, 1990, p722). They also found that autism “contributed significantly more to family stress than did cystic fibrosis” (Bouma and Schweitzer, 1990, p722), with 6 scales reaching significance for the autism group, and 3 for the cystic fibrosis group when compared to the matched controls. There was no effect of the number of children in the family, as was reported in some previous studies. A slight drawback with this study is the imperfect sample matching, with variance in the number of boys and girls, and lone-parents between groups. It should be noted that the 4:1 ratio of boys to girls in the prevalence of autism makes the balancing of clinical samples difficult.

Konstantareas, Homatidis and Plowright, (1992) developed their so-called ‘Clarke Modification of the QRS’ which they aimed at making more specific to parents of children with developmental and psychological problems, rather than physical or medical problems. They used a sample of 367 parents of children aged 7-9 years. They
divided this into the diagnostic groups ‘autism’, ‘mental retardation’, ‘learning disability’, and ‘normal’, which were matched for sex, age (mental age in the MR group), birth order, socio-economic status, and mother’s employment status. Between group differences were established on 8 of the 9 scales employed (with gender differences found on 3 of 9 scales, see following section). The measure could discriminate ‘controls’ from the ‘autism’ and ‘mentally retarded’ groups, but not between the ‘autism’ and ‘mentally retarded’ groups themselves. The ‘learning disability’ group differed from the ‘control’ group across 6 of 9 scales, and the ‘mentally retarded’ group differed from the ‘learning disabled’ group on 7 of 9 scales.

Despite a flaw with the groups used, this study shows not only that the newly developed instrument (Clarke QRS) has significant discriminative utility, but also that it is possible to find substantial differences in perceived parenting stress across diagnostic groups (including autism) if sensitive measures are used.

The Parenting Stress Index [PSI]:

The Parenting Stress Index (Abidin, 1995 original version 1983) is based on research which identified aspects such as parent characteristics, child characteristics, family context, and life stress as being key to understanding the parent-child system under stress. It was designed to identify parent-child systems under excessive stress, in order that early intervention could occur (Abidin, 1995). As well as an overall stress score (for the parent-child dyad, not purely the parent), scores on the 3 domains (Child, Parent, Life Stress) and sub-domains (6 within Child, and 7 within Parent) can be derived. Norms are provided for a mixed race USA sample of mothers (N=2633) and a small group of fathers (N=200). The normative data suggest that the fathers score lower across most of the scales of the PSI compared to mothers. Internal consistency (0.70 Child, 0.90 Total) is good. Test-retest reliability varies across domains but is acceptable (0.63 Child, 0.96 Total). Evidence from factor analysis indicate that the different scales measure different sources of stress (Abidin, 1995). There is substantial evidence for the robustness of the instrument across cultures and socio-economic diversity (Abidin, 1995).
Research using the PSI:

Fisman, Wolf, and Noh, (1989) compared parents of developmentally normal children (N=62), children with autism (N=31), and children with Down syndrome (N=31). Parents in the autism group scored highest on the stress measure, followed by the Down syndrome group and then the normal group.

Beckman, (1991) cited in Abidin, (1995) looked at differences across a group of parents of children with varied diagnoses (including autism) but all with moderate to severe developmental delay, and a group of parents of developmentally normal children. Parents of children with disabilities reported higher stress on both ‘Child’ and ‘Parent’ domains of the PSI but with large variability within diagnostic groups. However, it is likely that this is due to the small numbers in each diagnostic group and the influence of any number of intervening variables (see below).

Donenberg and Baker, (1993) compared parents of children with externalising behaviour problems to those with autism, and found that similar levels and patterns of stress were reported across the scales of the Parenting Stress Index, with most of the stress being attributable to the domain which measures child characteristics.

Research using the PSI to address the issue of cross-diagnosis difference is not well developed, but the instrument would seem to be appropriate for this purpose, although because of its robustness and the wide scope of its sub-scales, its applicability directly to autism is not yet clear.

Research Using other Instruments:

Rodrique, Morgan and Geffken, (1992) compared fathers across diagnostic groups (autism, Down syndrome and controls) using a well defined sample (N=60) and a multi-component assessment involving questionnaires on coping, social support, sense of competence, marital adjustment, and a live play task with their child. They found that fathers differed across groups in the specific coping strategies which they employed (e.g. more wish-fulfilling fantasy in the autism group), their ratings of the impact of the child’s disorder on the family (Down and autism group higher than controls), and caretaker burden. This study represents the limits of the research into
fathers parental stress so far, using as it does a sound multi-component method, well known instruments and having a well specified and exclusively male sample. However, parenting stress was derived from measures of parenting competence etc. and not directly assessed using the PSI or QRS.

Parallel developments:
As research progressed in comparing parents of different clinical populations, a number of intervening demographic and social variables have been identified. These have been incorporated into the matching of control groups in the later and more methodologically sound studies. Holroyd, Brown, Wikler and Simmons, (1975) found that parental stress was positively correlated with the age of the child. Bristol, (1980 cited in Morgan 1988) found in 40 mothers of children with autism, that parental stress varied with social support, child characteristics, availability of care services, and gender of the child (boys linked to higher stress in mothers). Bristol and Schopler, (1983) report similarly to Holroyd et al., (1975), that the child’s age was associated with changes in parental stress, with teenagers with autism have more highly stressed parents than younger children.

One difficulty with research comparing parents of different clinical groups, is that without control groups matched for the variables now found to be linked to changes in parental stress, it is difficult to conclude whether parents of children with autism truly are more stressed than parents of other groups of children, or whether such a result was due to an intervening variable, or an artefact of the instrument used to measure parental stress. However, over the years, findings for the categorical view (that parenting stress patterns are closely linked to the specific challenges associated with caring for children with different diagnoses) have become more clear as improvements in methodology and measurement have taken place. The latest studies (and some better designed earlier ones), using specific parental stress measures (such as the QRS described above), and controlling for the important intervening variables mentioned, have provided strong evidence for such a view (e.g. Konstantareas et al., 1992).
Another difficulty with this line of research in relation to the central interest of this review, is the extent to which the findings from mixed groups of parents, or from groups of mothers, can be generalised to fathers (see section F).

It should be noted that other socio-ecological variables have been investigated, such as family cohesion and marital satisfaction, but these are seldom used in the definition of matched control groups and so are not dealt with specifically here. The interest in these variables and their measurement is becoming increasingly popular as family systems research continues.

E: Fathers’ and Mothers’ Stress and Coping, same or different?
Most of the studies which have been conducted into parental stress in parents of children with autism, have relied on samples of mothers, or mixed samples. Whether this was due to a lack of appreciation of the importance of stress in fathers, or just due to difficulties in recruiting fathers into research samples, is not entirely clear. DeMyer, (1979) in a central text on the subject of parenting in autism puts forward the view that fathers as well as mothers are at risk of psychiatric or stress disorders. More research seems to have occurred since the resurgence of interest in the role of the father in child development, alongside a political shift which occurred in the USA in the late 80s (Marsiglio, Amato, Day and Lamb, 2000). For example, Amato and Rivera, (1999) using data from the very large (N=994) American “National Survey of Families and Households” and controlling for important variables such as maternal involvement, found that “positive paternal and maternal involvement were independently and significantly associated” with a reduction in children’s behaviour problems (Sweet, Bumpass, and Call, 1988 cited in Amato and Rivera, 1999, p375).

In this section, studies which have examined parent gender differences on measures of stress and coping (often only as post-hoc analyses) are described.

Wishart, Bidder and Gray, (1980) cited in Rodrigue, Morgan and Geffken, (1992) found that fathers of children with developmental delays differed from mothers of the same group in that they were less satisfied with the professional services offered for their child. This is interesting, as fathers have been found to be less involved in child health care services (DeMyer, 1979). Tavormina, et al., (1981) examined stress and
coping in 93 fathers and 133 mothers of children with a variety of physical disabilities. Although mothers reported more stress than fathers, both genders reported that their lives were centred on the child’s needs.

Goldberg, Marcovitch, MacGregor and Lojkasek, (1986) measured self-esteem, locus of control and parental stress and support in 59 families, finding their measures able to find differences between parents of children with Down’s syndrome, neurological, and developmental delay of unknown aetiology. They also examined gender differences and they concluded that “fathers reported fewer distress symptoms, higher self-esteem, more internal locus of control, and less support than did mothers” (Goldberg, Marcovitch, MacGregor and Lojkasek, 1986, p610). This suggests that the effects of a disabled child on fathers is different to that on mothers.

Beckman, (1991 cited in Abidin, 1995) in comparing parents of children with mixed disabilities (including autism) and normal children using the PSI, found that mothers and fathers reported similarly high stress levels within the Child Domain. Mothers however, reported more stress than fathers in the Parent domain. Further differences were found between the sub-domain scores of mothers and fathers. Also, fathers’ life stress was associated with the level of formal support they reported, whereas this was not significant for mothers. It is interesting to note that this might be related to the finding that fathers were less satisfied with formal supports for their autistic child than mothers were (Wishart, Bidder and Gray, 1980 cited in Rodrigue, Morgan and Geffken, 1992).

Milgram and Atzil, (1988) employing a cognitive model of stress, used both subjective and objective measures, to see which were more predictive of parents’ life satisfaction (held to be inversely related to parenting stress). They took subjective measures of life satisfaction, parenting burden, and perceived fairness of this burden. Objective measures were ratings of the child’s behaviour by a head-teacher and a psychologist, and ratings on the AAMD, an adaptive behaviour inventory (Lambert, Windmiller, Cole and Figueroa, 1974 cited in Milgram and Atzil, 1988).
They used an Israeli sample of 23 mothers and 23 fathers of children with autism. Mothers and fathers agreed that fathers did about $1/3^{rd}$ and mothers $2/3^{rd}$s of the childcare. They found that mothers' life satisfaction was predicted by the relative burden they were assuming, whereas for fathers, life satisfaction was predicted by the actual burden they were assuming. There was no significant relationship between life satisfaction and any of the objective measures taken. Mean satisfaction scores were slightly higher for fathers than mothers ($t=1.69, P<0.05$), though both fell in the normal range for their instrument (for which reliability / validity data are not clear).

These findings suggest that "life satisfaction is more affected by what parents do to cope with their child's atypical development than by the atypical development itself" (Milgram and Atzil, 1988, p422). Although this is an interesting study showing differences in what mothers and fathers do (the $1/3^{rd} 2/3^{rd}$ burden split is a robust cross-cultural finding reported since DeMyer, 1979), it is unfortunate that the researchers did not use a better specified subjective measure of perceived stress.

Rodrigue, Morgan and Geffken, (1992) compared 60 fathers across 3 diagnostic groups (see section D). The authors additionally found differences between their fathers' data and that from their own previous study of mothers of similar diagnostic groups. The authors comment that their data indicates that mothers show more caretaker burden than fathers (agreeing with previous studies, see above), and that fathers report more change to their social activities as a consequence of their child's disability than do mothers. Although this last finding is bound to be mediated by cultural patterns of maternal and paternal employment and care-giving roles, it is worthy of consideration in further research (see section F).

Konstantareas, Homatidis and Plowright, (1992) found in their cross-diagnosis study, (see section D) that in all cases (autism, mental retardation, learning disabled, and matched controls) mothers rated higher overall stress than fathers using their own Clarke Modification of the QRS. Mothers and fathers differed significantly on the 'Time Demands', 'Presenting Symptoms', and 'Sacrifice/Martyrdom' scales. There was also an interaction between parent gender and the 'Community Reaction' scale in the parents of the control children, with fathers reporting more associated stress on this
scale than mothers. They report that the Clarke QRS was able to discriminate between two sets of fathers. Those of the ‘normal’ and ‘learning disabled’ children on the one hand, and those of the ‘autistic’ and ‘mentally retarded’ children on the other. For mothers however, the instrument was able to discriminate between three sets, being able to additionally tease apart mothers of ‘normal’ and ‘learning disabled’ children. These results indicate that there are some differences between mothers and fathers of autistic children (and other groups) in overall stress, the pattern of reported stress, and the applicability of the Clarke QRS (and possibly other parenting stress measures) to samples of fathers.

These cross-gender findings would benefit from replication using more precisely defined groups of children, as the present study is not clear as to the exact criteria for inclusion in the groups. Furthermore, in defending the discriminative power of their instrument, they claim that the ‘mentally retarded’ group may well be comparable to the ‘autism’ group as 80% of children with autism may have similar cognitive deficits. But this is not satisfactory, as we would ideally wish to develop measures which would be able to tease apart the very specific difficulties associated with raising an autistic child, and one with so described ‘mental retardation’. However, the study does have several strong points including the sample size, the use of other measures to assess validity, and groups including a control group matched for sex, age, birth order, SES, mother’s working status, and where necessary the child’s mental age.
F: Summary and Conclusions:
As described in the review, despite reliance on questionnaire and survey methods, and an over reliance on female parent samples, there appear to be some strong findings indicating that autism is strongly linked to parental stress, in many cases more so than other more life-threatening conditions (see Section D).

The measurement of stress in parents has developed from the use of general depression inventories to the development of specific stress and coping measures (e.g. QRS and PSI). The general scope or specificity of these measures, as well as their psychometric properties and validity should be considered by those designing future studies. Recent studies are beginning to use multi-component assessments, which may lead to a finer analysis of the individual components and buffers which lead to the expression of parenting stress.

As studies progressed, several important intervening variables which effect the expression of parental stress were identified. These include lone parenting, the gender of the parent and child, family socio-economic status, and in some studies, family size (see Section D).

Throughout this review stress and coping research has been dealt with as a single topic, as a reflection of the research into stress in parents of clinical groups. However, it should be noted that there are specific models and instruments designed to measure coping (Hymovich, and Hagopian, 1992), and whole areas of research into coping efforts along cognitive, emotional and practical dimensions which have not been reviewed here. It can be argued that instruments such as the PSI and QRS reflect not only stress, but to a large extent personal and cognitive coping strategies.

Research methodologies in this field have been limited by practical difficulties of access to appropriate samples, by difficulties with obtaining longitudinal data, together with ethical considerations which are at the fore in the study of chronic childhood conditions. However, both quantitative and qualitative methods have been used within this field of research. The most prevalent are quantitative methods, most notably exemplified by the large-sample survey studies carried out in the USA from which
robust findings on general parenting stress have emerged (The National Survey of Families and Households; Sweet, Bumpass, and Call, 1988 cited in Amato and Rivera, 1999).

The parental stress and coping research reviewed here, has been conducted largely in the USA, Canada, Australia, and the United Kingdom. Though many studies note the Caucasian middle class bias in their sampling, only the American survey researchers make any attempt to access other groups specifically (Amato and Rivera, 1999).

Future quantitative research could usefully seek to replicate cross-diagnosis comparisons using samples of fathers, and more ethnically and culturally diverse samples. There may be important information about the effects of social-roles of fathering, which could be gleaned from comparison of matched father samples from cultures differing in social role definitions.

The results of Goldberg, et al. (1986) showing differences between mothers and fathers on stress, locus of control, and self-esteem measures are of interest. Within a cognitive model of stress it would be postulated that the higher reports on locus of control and self-esteem might ameliorate fathers’ stress, whereas the lack of social support would be considered likely to increase the fathers perceived stress. Controlling for (or at least measuring) locus of control and self esteem in a future study might help to conclude whether the effect of a disabled child is the same on fathers as mothers, but that fathers have different buffers to stress such as a more internal locus of control.

It is insufficient just to accept the widely found result that fathers rate generally less stress than mothers on total parenting stress scores especially as the instruments designed to measure parenting stress have been developed mostly using samples of mothers. Replications of the previous research comparing across clinical child populations would best be done concurrently with matched groups of mothers, and groups of fathers, to avoid being misled by sampling, measurement differences or other threats to accurate cross-gender comparison.
Another finding worthy of further investigation is that fathers have reported more change to their social activities as a consequence of their child’s disability than mothers (Rodrigue, Morgan and Geffken, 1992). Trute and Hauch (1988) also found evidence of smaller social networks in fathers of children with developmental disorders compared to fathers of developmentally normal children. Studies, possibly using interviews with fathers might seek further detail as to when, how and why these changes (if they are substantiated) occur, and look at the impact upon fathers well-being of these changes. Again, cross cultural comparison, and links to cultural role definitions would be of interest in this area.

The lack of qualitative studies in comparison to quantitative research in the field has already been noted. However, one example is that of Midence and O’Neill (1999) who used a “grounded theory” approach (Strauss and Corbin, 1990) with interview data and a very small sample of parents, to develop an understanding of specific stresses and coping strategies in a particular target population. There are other examples such as Gray (1994). However these are so far of a pilot study nature and look more at coping than stress. Results from these studies should not be generalised far beyond the local samples used, however, they are of value in other ways.

It could be argued that exactly what is required in order to avoid being misled by previous mother-biased quantitative measures and results, is a careful exploration of exactly what constitutes ‘fathering stress’ in different clinical populations. Qualitative methods are suited to finding unexpected results, being able to approach people’s experiences without the burden and constraints of too rigid a theory. They may also more fully reflect individual heterogeneity which might otherwise be subsumed under ‘mean stress scores’. Such cross method corroboration would allow future researchers and clinicians to choose or design appropriate measures to assess aspects of stress in fathers of children with autism and other psychological, developmental and physical difficulties.
References:


Exploring the Experiences of Fathers of Young Children with Autistic Spectrum Disorders: A Qualitative Study

Major Research Project
Submitted July 2002

Word Count: 19,960
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>186</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>187</td>
</tr>
<tr>
<td>Introduction</td>
<td>188</td>
</tr>
<tr>
<td>Method and Procedure</td>
<td>200</td>
</tr>
<tr>
<td>Analysis and Results</td>
<td>207</td>
</tr>
<tr>
<td>Discussion</td>
<td>232</td>
</tr>
<tr>
<td>References</td>
<td>243</td>
</tr>
<tr>
<td>Appendix 1: Interview Schedule</td>
<td>249</td>
</tr>
<tr>
<td>Appendix 2: Participants’ Introduction Sheet</td>
<td>251</td>
</tr>
<tr>
<td>Appendix 3: Consent Form</td>
<td>253</td>
</tr>
<tr>
<td>Appendix 4: University Fast Track Ethics Committee Letter of Approval</td>
<td>255</td>
</tr>
<tr>
<td>Appendix 5: Sample Transcript - Colin</td>
<td>257</td>
</tr>
</tbody>
</table>

*Original page numbers appear in the transcript to allow referencing*
Abstract

Title
Exploring the Experiences of Fathers of Young Children with Autistic Spectrum Disorders: A Qualitative Study.

Objectives
To explore fathers’ definitions of the challenges arising from having a child with an autistic spectrum disorder [ASD]. To explore fathers’ responses to those challenges and how they related to services for their children. To compare and contrast this data with existing psychological literature.

Design
A semi-structured interview based qualitative study. Interpretative Phenomenological Analysis [IPA] (Smith, 1995) was used to analyse the data.

Setting and Participants
Participants were 8 fathers of children aged 3-6 years old who were attending, or had recently attended a specialist autistic spectrum disorders assessment nursery [Autism Assessment Nursery].

Main Outcome Measure
Semi-structured interview data.

Results and Conclusions
Fathers defined challenges as arising from the vulnerability of their child, time-related challenges, negative social judgements, difficult emotions, understanding autism, behaviour management and challenges arising from the educational system.

Participants’ responses included a problem solving approach, role adjustments within the family, marked changes to work and attitudes toward it, changes to personal social life, family activities and a shared proactive approach between the parental couple. Unexpectedly, participants reported benefits to their marital relationship stemming from this shared approach to their children’s needs.

Fathers experienced services as patchy and over-stretched. They noted the lack of male staff across services. Fathers experienced pre-school autism services as positive and inclusive. Participants expressed a wish for a collaborative approach and for clear recommendations on educational placements.

The relationship of the current data to existing research are discussed, as are ideas for future research and for service development.
Acknowledgements

I wish to thank sincerely the following people for their varied contributions to the research project.

The fathers who participated in the study.
*For their willingness to explore the impact on their lives of having a child with an autistic disorder, and the honesty with which they approached the interviews.*

The management and staff of the specialist autism assessment nursery.
*For allowing me to propose the research to them and then for their support in recruiting the fathers of children attending the nursery.*

Dr. Maxine Tostevin.
*For her support in setting up the research and recruiting the participants.*

Dr. Sarah Lovekin and Catherine Attridge.
*For their help in the later stages.*

Mick Finlay.
*For his supervision throughout the project.*

Members of the PsychD Qualitative Research Peer Group 2002.
*For their ideas on themes emerging from the first transcript and later discussion on varied research issues.*
Exploring the Experiences of Fathers of Young Children with Autistic Spectrum Disorders: A Qualitative Study

Introduction

Autistic Spectrum Disorders [ASDs] fall within the category of Pervasive Developmental Disorders [PDDs] in the DSM-IV (American Psychiatric Association [APA], 1994) and the ICD-10 (World Health Organisation [WHO], 1996) classification systems. ASD is a phrase commonly used by European professionals to describe Childhood Autism, Atypical Autism and Asperger's syndrome but excluding other PDDs.

Children with ASDs are described as having significant deficits in social development, language and imagination (Wing & Gould, 1979). These disorders can also be characterised by "severe and pervasive impairment in . . . reciprocal social interaction skills, communication skills, or the presence of stereotyped behaviour, interests and activities." (APA, 1994, p65). Prognosis for most children with PDDs is poor, with 60% being unable to lead an independent adult life (Gilberg, 1991). PDDs are estimated to effect 1 in 2000 to 1 in 500 children in the United States (Filipek, Accardo, Baranek, Cook, Dawson, Gordon, Gravel, Johnson, Kallen, Levy, Minshew, Prizant, Rapin, Rogers, Stone, Teplin, Tuchman & Volkmar, 1999). Autism, the most common PDD, has been estimated to effect 2-5 per 10000 children and a male to female ratio of 3:1 to 4:1 has been found consistently (Carr, 1999).

Because of complex social, behavioural and learning needs and the paucity of language in children with ASDs, it is expected that there would be significantly increased parental care burden (Bristol, 1984). Parents of children with ASDs have been found to report higher parental stress and also particular profiles of stress, compared to parents of children with other diagnoses such as cystic fibrosis (Bouma & Schweitzer, 1990), learning disability (Koegel, Loos, Dirlich-Wilhelm, Robbins & Pleinis, 1992) and Down syndrome (Holroyd & MacArthur, 1976).
Differences in stress and coping between fathers of children with disabilities and developmentally normal children have been reported as they have for mothers. Trute & Hauch (1988) found that fathers of children with developmental delays had smaller social networks than fathers of developmentally normal children. Rodrigue, Morgan & Geffken (1992) used the Ways of Coping Scale [WCS] (Lazarus & Folkman, 1984) and the Revised Impact on Family Scale (Stein & Jessop, 1985) with groups of 20 fathers of autistic, Down syndrome and developmentally normal children. Despite the limitation inherent in using the WCS which imposes particular definitions and forms of coping on participants, fathers in the autism and Down syndrome groups reported more use of 'wish-fulfilling fantasy' and 'information seeking' than other fathers. Fathers in these two groups also reported greater financial impact and a greater level of disruption of family activities.

Although parents of children with and without disabilities have been distinguished by measures of parenting stress and coping, at the detailed level of exactly what parents find stressful, what variables mediate this and what coping strategies are used, the research findings have been rather contradictory or inconclusive (Davis, 1993). Explanations for why this has been so could include criticisms of the models of stress and coping used, the narrowly focused instruments used and the limitations of the methodologies employed so far.

Methods and Measures used Previously:
The majority of studies in this area have used quantitative methodologies and questionnaires based on general models of stress and coping (Midence & O'Neill, 1999; Gentil, 2001). They have sought to define characteristic stress profiles across the sub-scales of a small number of instruments, or to find correlations between groups' overall stress-scores and other variables. Although studies using these methods have been successful in achieving the aims described, they also have limitations. The variables examined can be thought of as falling into four classes. Child variables include the age, functional level and gender of the child. Family variables include size of the family and family cohesion. Less attention has been paid to the third and fourth classes of variable. These are parents' personal variables (appraisals, personality) and contextual variables (e.g. work stress, social support), with the exception of social support which
has been studied. Recently, more attention has been paid to these areas and has yielded some important results (Ostberg & Hagekull, 2000).

Two instruments have been widely used in this area of research and they are briefly critiqued below as this informs the alternative approach of the current study. The Questionnaire on Resources and Stress [QRS] (Holroyd, 1974) is a popular measure developed in the U.S.A.. The original version contained 285 yes/no items across 15 sub-scales. These were said to access 'respondent factors', 'family factors' and 'child factors'. After criticism of its statistical properties, several short-forms were developed (Salisbury, 1986). Criticisms of these instruments could include the lack of inclusion of social-support or a wide enough range of family-external variables (e.g. work stresses), the lack of weight given to personal variables (other than health and depression), lack of fathers in the standardisation and the age-sensitivity of many of the items. Salisbury notes that the often used QRS short-form should not be used alone to assess family stress and resources.

Another commonly used measure is the Parenting Stress Index [PSI] (Abidin, 1995) which is now in its third edition and significantly improved from the original. This was also developed in the U.S.A. in the 1980's following the stress and coping model of Lazarus and Folkman (Lazarus & Folkman, 1984) and it is reasonably statistically robust (Abidin, 1995; Gentil, 2001). It contains a 'Child Domain' (e.g. hyperactivity, demandingness) and a 'Parent Domain' (e.g. role restriction, health) consisting of Likert scale items (strongly agree to strongly disagree). Earlier versions were more narrowly focused on child variables and less widely standardised. The latest edition PSI standardisation sample was still heavily biased toward mothers' experiences of stress (2633 mothers and only 200 fathers). Only major events, such as divorce and pregnancy are listed on the optional 'Life Events' scale. While its coverage of child variables is comprehensive, criticisms could be made of the gender bias in generating the instrument, the lack of weight given to more subtle personal variables and the lack of weight given to contextual pressures (e.g. work stress, financial problems).

Although these two instruments aim to reflect child, family and to some extent parent variables, both limit participants' responses in several ways. As they were derived
from studies which sought to discriminate between groups of parents of children with
different disorders, they define what is considered a resource, they define what is
considered to be stressful and they do not allow sufficient weighting of responses to
reflect individual differences or the low-level contextual stressors which have recently
been found to be important (Ostberg and Hagekull, 2000). So although they may
accurately reflect the frequency of child behaviours presented in different disorders, the
drawback of using statistically derived but rigid measures is that they may not reflect
important idiosyncratic small-group characteristics because they were created by and
designed to, compare a sample's score to a statistical (and hence culturally dependent)
norm. They also only measure a defined repertoire of stressors and coping strategies,
i.e. those considered in the original instrument design.

Similarly, semi-diagnostic measures of child symptom severity such as the Childhood
Autism rating Scale [CARS] (Schopler, Reichler, & Renner, 1986) and the Autism
Behaviour Checklist [ABC] (Krug, Arick & Almond, 1979 cited in Kasari & Sigman,
1997) also limit the possibilities for research to reflect individual, cultural and gender
differences by constraining their participants' definitions of challenges presented by the
child. They also reduce participants' appraisals of the child's behaviours to four point
ratings (only the latest versions moved away from yes / no items) and hence may
misrepresent the impact of some behaviours upon parents.

The current study was largely informed by the useful findings and the shortcomings of
this strand of quantitative research. Therefore relevant findings are discussed below.

Relevant Findings on Child Variables:
PSI profiles for parents of children with developmental delays (no data given for
children with ASDs) indicate increased scores on the 'Acceptability' sub-scale, with
relatively high scores across the rest of the 'Child domain'. A lower and reasonably
flat profile is seen within the 'Parent domain' (Abidin, 1995). As the 'Acceptability'
items hinge on social feedback, this area should be explored in fathers' accounts.

Findings on child age have been inconsistent. Several studies found that the increasing
age of the child with an ASD was linked to increases in measures of parental stress
(Baxter, 1992; Baxter, Cummins & Polak, 1995). However using the QRS, Koegel et al. (1992) found that the characteristic stress profile of mothers of autistic children did not vary significantly with child age. Establishing a child age criteria for the current sample was therefore considered appropriate.

Bebko, Konstantareas and Springer (1987) found that mothers and fathers agreed that the most stressful aspects of their child’s disorder were ‘cognitive impairment’ and ‘limitations on language use’. This study used the CARS (Schopler, Reichler & Renner, 1986) checklist and therefore focused on child variables.

Salisbury’s factor analytic study (Salisbury, 1986) (N = approx 400) used a short-form of the QRS with parents of handicapped (mixed diagnosis) and non-handicapped children, with no data given on parental gender. Discriminative factors which emerged were ‘life-span care’, ‘cognitive impairment’, ‘child characteristics’, ‘family disharmony’, ‘pessimism’, ‘physical limitations’ and ‘financial stress’ (Salisbury, 1986). These discriminative factors indicate some areas of challenge to mothers of children with developmental disabilities.

A noteworthy study which used observational measures of parent-child interactions, the PSI and the ABC, found a link between reported parental stress and the degree of lack of social responsiveness of the child (Kasari & Sigman, 1997). Exploring why and how the social responsiveness of the child effects parental stress is thus indicated.

Another important study, although not specifically addressing parenting of children with ASDs, used a multidimensional model derived from Crnic, Friedrich and Greenberg (1983) and an array of checklists as described above, to look at child and parent variables together. The sample was 48 mothers and 48 fathers of children aged 32-168 months old with Down syndrome or Cerebral Palsy. The communicative level of the children was found to mediate parental stress more strongly for fathers than for mothers. These researchers also found that boys were associated with higher parental stress for both mothers and fathers. The researchers’ model accounted for approximately 50% of the sample variance on the stress measure (QRS) with all the factors added (Frey, Greenberg & Fewell, 1989).
Thus child variables found to be important in mediating standard measures of parental stress include, gender, social responsiveness, level of communication, cognitive level, acceptability, life-span care, family disharmony, pessimism, physical limitations, financial stress and possibly age. These results also suggest that parental variables, including gender, interact with these child variables.

Relevant Findings on Parental Variables:
Bebko, Konstantareas and Springer (1987) mentioned previously, found that fathers of children with ASDs differed from mothers in that they continued to show high levels of stress with the increasing age of the child, despite both groups reporting a reduction in the child’s symptom severity and agreeing on the most stressful aspects of the child disability using the CARS. The differential impact of child age on parental stress across gender might indicate that there are different sources of stress for fathers which were not accessed by the CARS checklist.

Koegel et al. (1992), in a well controlled study using the QRS on 50 representative families, found that mothers of children with autism scored in the normal range on standardised measures of personality, marital adjustment and family functioning. They concluded that there was a specific stress pattern in mothers of children with autism, that was not linked to child age, cultural / geographic environment or the child’s functioning level. They concluded that parenting stressors were therefore highly variable and specific. This finding suggests the importance of looking at the interactions of child variables and parent variables together or looking at contextual variables outside of the scope of the above measures.

Frey, Greenberg and Fewell (1989), in the study mentioned previously, found that social network and parental beliefs were important mediators of parenting stress and psychological distress using a number of questionnaires in parallel. There was a gender difference in the most important component of the social network. This was found to be a lack of criticism in the network for fathers and the amount of support for mothers.
Parental beliefs were found to be strongly related to parental stress and distress. The ‘comparative appraisal’ component which centres on beliefs about the family and child in comparison to others, was strongly indicated (using their own 20 item instrument). The authors note that the comparative frame of reference which parents use to evaluate themselves and their child is extremely important in moderating stress and coping (Frey et al., 1989).

The percentage of ‘problem focused’ and ‘seeks social support’ problem solving as defined by the Revised Ways of Coping Checklist (Vitaliano, Maiuo, Russo & Becker, 1987) was linked to better outcomes in mothers. In fathers, ‘seeks social support’ was not linked to better outcomes on parental stress or psychological distress. The coping styles ‘avoidance’ and ‘wishful thinking’ were associated with negative outcomes in both parents. Ratings of coping efficacy and of the spouse’s coping efficacy were also important mediators across outcome measures (Frey et al., 1989).

Ostberg and Hagekull (2000), using a Swedish adaptation of the PSI and other measures with multivariate structural equation modelling, examined a population sample (N = 1081) of mothers of children aged 3 months to 6 years. Although not looking at mothers of children with ASDs, this study identified some buffers to and components of mothers’ stress scores. ‘High workload’, ‘low social support’, ‘negative life events’, ‘perception of the child as fussy/difficult’, ‘child care-taking hassles’, ‘more children in the family’ and ‘higher maternal age’ were the salient components of the defined model. Together these factors accounted for 48% of the sample variance on the PSI stress measure.

Their model neglected the stress of work outside the home as a potential stressor, as well as parent personality characteristics, coping strategies and the sample contained no fathers. Importantly though, as did Frey et al. (1989) previously, the researchers noted that parents’ perceptions and attributions about their children’s behaviour are linked to parental stress at least as powerfully as the objectively defined child variables previously given primacy in the literature (Ostberg & Hagekull, 2000).
So in summary, previous research has identified family and parental variables which impact on parents’ (mostly mothers’) reports of parenting stress. These variables include attributions about the child and its behaviour, high workload, low social support, negative life events, care taking hassles, greater number of children, higher maternal age and spouse’s coping efficacy. Social support has also been identified, with a lack of criticism in the network being important for fathers and amount of support being important for mothers. Coping strategies found to be useful include problem focused coping (both genders) and seeking social support (mothers only). Strategies linked to negative outcomes include avoidance and wishful thinking.

**Confounding Mothers and Fathers in Quantitative research:**
The majority of previous psychological research into parents of children with disabilities (including ASDs) has confounded data on mothers’ and fathers’ stress and coping or has under-represented fathers (Gentil, 2001). Of those that have accessed fathers’ opinions, several have found gender differences (Bebko et al., 1987; Frey et al., 1989; Wishart et al., 1980 cited in Rodrigue et al., 1992). Further findings of gender differences include that fathers of children with Down syndrome or neurological difficulties reported fewer symptoms of distress, greater self-esteem, greater internal locus of control and less support than did mothers (Goldberg, Marcovitch, MacGregor & Lojkasek, 1986). However, because of the instruments used and the lack of control for care-involvement, this comparison is suggestive rather than robust. Similarly, Konstanareas & Houmatidis (1992) found that the correlation between the child’s symptom severity and parental stress was weaker in fathers than mothers of autistic children aged 6 to 18 years using a Likert rating scale alongside the CARS (Schopler, Reichler & Renner, 1986) suggesting that fathers’ parental stress was less closely linked to child variables than to parent, family or contextual variables.

**Parents’ Interaction with Services:**
Poor parent-professional agreement about a child’s diagnosis was found to be a factor in low compliance with recommendations (Glaun, Cole & Reddihough, 1998). Fathers were found to be less satisfied than mothers with the services provided for their developmentally delayed child by Wishart, Bidder & Gray (1980 cited in Rodrigue et
al., 1992). Diagnostic disagreements would likely be exacerbated by a lack of inclusion of fathers in services. In ASDs where the diagnostic process often takes many months or years and where early family-based interventions are important (Howlin & Moore, 1997), inclusion could be considered to be of heightened importance. In a study where children attended and parents were included in a specialist autism service, parental stress was found not to differ significantly from that in control families (Koegel et al. 1983). Together these results suggest that inclusion of parents and their children in appropriate autism services and the process by which this inclusion and satisfaction can be fostered, would be a useful area for clinicians to have further information on.

Emergence of Qualitative Analyses:
While many quantitative studies have been conducted over the last thirty years, research using qualitative methodologies has only emerged recently. This approach has merits in producing a rich understanding of the social and interpersonal processes underlying fatherhood (Marsiglio, Amato, Day & Lamb, 2000). However, while qualitative studies can reflect the idiosyncrasies of local samples they are limited in their generalisability. Data at the descriptive level of personal coping and cognitive-appraisal would be worthwhile as it is likely to be more informative than group data on standardised measures of parental stress or family functioning (Tams, 2001). Marsiglio et al. (2000) in their review of fatherhood research discuss the need for future research to look at how ecological contexts (contextual variables) effect fatherhood patterns and how fathering roles are defined or co-constructed in diverse contexts. These aims, within a single context are addressed in the current study.

The small number of published qualitative studies have begun to provide some useful insights into the individual beliefs, relevant stressors and coping efforts of parents of children with ASDs. Gray (1994) conducted a study which contained quantitative and qualitative phases with a sample of 33 parents of children with ASDs in Australia. The children were 6 to 12 years old, 88% lived at home and 66.7% were boys. Stressors reported as being most serious were, lack of normal language, disruptive / violent behaviour, inappropriate eating / toileting and inappropriate sexual expression. Parents reported a wide range of coping strategies. The most common strategies were use of
services, family support, social withdrawal, religion, normalisation and individualism (including joining pressure groups).

Midence and O’Neill (1999) conducted a pilot study in North Wales, which was previously found to be a geographical area where parental satisfaction with diagnosis was poor (Howlin & Moore, 1997). The authors’ focus was on the diagnostic experiences of 4 families of children with ASDs now aged 9 to 12 years who had been diagnosed between the ages of 3 and 7 years. Identified categories of stressor were ‘behaviour development’, ‘confusion’, ‘incorrect diagnosis’, ‘autism’, ‘support’ and ‘acceptance / adaptation’. Parents reported how they experienced confusion, despair and self-blame over the fact that their child was ‘different’, particularly before diagnosis. Participants reported negative experiences of taking their concerns into primary care services. They reported relief at the final diagnosis given and noted the importance of having a label in helping them resolve their difficult emotions. Participants reported that things were made worse because autism was an ‘invisible condition’, though the method of action for this was not clear. Parents noted the need for both practical and emotional support. Parents felt that acceptance of the diagnosis and acceptance that autism was an integral part of the child was important for successful adaptation.

Tams (2001) interviewed the parents of 10 children with ASDs aged 4 to 18 years of age (9 boys and 8 living with their parents) and used grounded theory to analyse the data. The heterogeneity of autism was identified, including common aspects of vulnerability, language difficulties, behaviour problems and normal appearance. ‘Real life versus media portrayal’ and related themes indicated that parents thought their children did not fit the classic picture of autism and were more affectionate or less withdrawn than this picture portrayed. Parental perceptions of their roles and the effects of autism on them illustrated themes of battling for the diagnosis and for services, behaviour management difficulties and other people’s lack of understanding of the condition. Parents noted a drive to become experts on the condition or to join support groups. The author notes the uniqueness of the parents’ constructions and highlights that parents may move from seeing autism as external to the child to accepting it as part of the child. This point applied only to parents who felt their child
had ‘become’ autistic during early childhood rather than those who were aware of difficulties from infancy. The author also highlights the importance for parents to ‘make sense’ of autism and how this improves coping and adaptation.

Confounding Mothers and Fathers in Qualitative research:
Unfortunately these studies have, as many quantitative studies did previously, confounded mothers’ and fathers’ experiences or under-represented fathers (Gray, Tams, 2001; Midence & O’Neill, 1999). Gray’s qualitative sample comprised 24 mothers and 9 fathers (Gray, 1994). The study’s aim was to explore the couples’ stresses and coping strategies, rather than those of fathers as individuals. To this end most of the interviews were of both parents simultaneously. Midence and O’Neill (1999) used a sample of four parental couples. Two couples took part together, with one father and one mother being interviewed separately. Gender differences were not examined. Tams (2001) conducted ten interviews with a total of ten mothers and two fathers, but no further details are given and all responses are described in terms of ‘parental’ views without reference to any gender differences.

Summary:
Within this literature there are complex and sometimes contradictory findings, as well as findings which would benefit from further exploration. Arguably there has been a lack of exploration of personal and contextual variables. There has been an under-representation of fathers in research samples. Therefore a rationale emerges for exploring fathers’ definitions of challenges and responses arising from parenting a child with an ASD using a qualitative method.

In this study the experiences of fathers of children aged 3-6 years of age with Autistic Spectrum Disorders and who had attended a specific Autism Assessment Nursery were explored using semi-structured interviews and Interpretative Phenomenological Analysis [IPA] (Smith, Jarman & Osborn, 1999). The study aimed to explore how this particular group of fathers defined the challenges arising from their child’s assessment, diagnosis and care, how they responded to those challenges and how they related to services.
Because previous quantitative research is best placed to, and has successfully established the frequencies of specific objectively defined behaviours presented by samples of children with ASDs, this is not explored directly in this study. Thus the focus of the study is not on specific behaviours and coping strategies at this level, but on definitions of challenges and coping responses at a more interpretative level.

The current study utilised a social constructionist perspective to examine fathers' individual definitions of challenge and response, so that theoretically determined concepts such as "coping" and "stress" would not limit participants' responses as greatly as in previous studies. The study took the position that the data were a reflection, based in and biased by language, of some of the conscious and unconscious processes which fathers held to be important. The research did not posit or test any hypotheses.
Method and Procedure

Epistemology:
In order to give a context for the findings, analysis and conclusions of the study this section further describes the epistemological position of the research. The study was based within a phenomenological perspective. Phenomenology at its root, “is interested in the world as it is experienced by human beings within particular contexts and at particular times” (Willig, 2001. Pg 51). In this study the phenomenon to be explored was fathers’ accounts of their experiences of parenting a child with an ASD. I (the researcher) do not claim to have put aside my personal perspective or psychological knowledge, but aimed to make their impact explicit and to keep the analysis (the interpretation) accurately grounded in the fathers’ accounts following the method of Interpretative Phenomenological Analysis [IPA] (Smith et al. 1999).

First names are used throughout the text to identify the participants, so that their individual stories and concerns can emerge. Similarly I refer to the researcher’s actions in the first person, using the I form in most text and “Andy” in interview quotations. This is common practice for studies using IPA and is consistent with the epistemological position of this study. Writing in this form reminds the reader that the interpreted account does not aim to be “true” in the positivist sense, but that it is a personal interpretation of a personal interaction based in a particular context.

As discussed in the Recruitment section the sample was somewhat homogeneous. This was also consistent with the epistemology of the research. The research did not aim to be widely generalisable, or comment on how fathers in different contexts would experience challenge. The research aimed to explore a particular group of fathers’ experiences as they defined them, their understanding of the impact of the experiences and their responses to them. The context within which these findings was set was that of the fathers’ own experiences of the local health and educational provision. As such the research aimed to make explicit the individual participants’ experiences and interpret them within their own context. Thus the similarities and differences between the fathers’ accounts are more illustrative as a result of the sample’s homogeneity and shared context.
Ethical Issues:
A draft research proposal including a Consent Protocol and Participant Information Sheet (Appendices 2 & 3) were designed and discussed with supervisors. The draft proposal was presented to the management committee of the Autism Assessment Nursery from which the participants would be invited to take part. The committee felt that the study was appropriate, addressed some of their own concerns and would not cause distress or harm to the participants. The proposal was then submitted to the appropriate NHS Trust research officer and Local Research Ethics Committee. Their approvals were granted (Appendix 4) with minor alterations to the recruitment information.

Recruitment:
Participants were recruited through an Autism Assessment Nursery in the south of England. This was a recently developed service (open two years) specialising in the assessment and nursery care of pre-school aged children suspected of having autistic spectrum disorders.

Theoretical sampling, a concept recommended by Henwood and Pigeon (1992) as a method for increasing quality in qualitative research, was undertaken at the design stage. To this end no exclusion criteria were put in place to ensure that the full range of circumstances and life-experience which local fathers possessed, would be reflected by the research sample. The Autism Assessment Nursery had originally had less than ten places, increased to approximately fifteen in the year that the study took place. The Autism Assessment Nursery staff handed information sheets (Appendix 2) to parents (both mothers and fathers) whose children attended the service over a period of six months. Fathers who were interested in taking part were asked to telephone the researcher.

Participants:
Nine fathers contacted the researcher. One person withdrew having shown interest, due to a change in personal circumstances. Thus the sample consisted of 8 fathers whose children (aged 3-6 years of age) had attended the Autism Assessment Nursery
in the year in which recruitment had begun. All the fathers except one were white U.K. citizens and all were between the ages of 30 and 45 years of age. They lived in an affluent county in the south of England. All the fathers were cohabiting with their spouse or partner in a family home with the autistic child who had attended the Autism Assessment Nursery. All of the fathers were currently employed in semi-skilled, skilled or professional jobs.

Figure 1: Sample Characteristics

<table>
<thead>
<tr>
<th>Name</th>
<th>Marital Status</th>
<th>Child (ASD)</th>
<th>Siblings (Non-ASD)</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phil</td>
<td>Married</td>
<td>Bob 5</td>
<td>Carl 8</td>
<td>Full-time 9-5</td>
</tr>
<tr>
<td>Colin</td>
<td>Married</td>
<td>Chelsea 4½</td>
<td>Joanna 6½</td>
<td>Full-time 9-5</td>
</tr>
<tr>
<td>Henry</td>
<td>Married</td>
<td>Jimmy 3</td>
<td>Jemima 2</td>
<td>Self Emp</td>
</tr>
<tr>
<td>Paul</td>
<td>Married</td>
<td>Jesse 5</td>
<td>Jemima 13, Doug 17, James 14</td>
<td>Self Emp</td>
</tr>
<tr>
<td>Mark</td>
<td>Married</td>
<td>Andrew 3½</td>
<td>John 5, Felix 2</td>
<td>Full-time 9-5</td>
</tr>
<tr>
<td>Steve</td>
<td>Married</td>
<td>David 6</td>
<td>Gemma 7½</td>
<td>Full-time 9-5</td>
</tr>
<tr>
<td>Ivan</td>
<td>Married</td>
<td>Greg 4</td>
<td>Chip 7</td>
<td>Full-time 9-5</td>
</tr>
<tr>
<td>Tom</td>
<td>Married</td>
<td>Toby 3½</td>
<td>Alice 1½</td>
<td>Full-time 9-5</td>
</tr>
</tbody>
</table>

Although the sample size used here (N=8) would be considered small for a quantitative analysis, for a qualitative analysis of the detail used here it is reasonable for both submission for doctoral qualifications and peer reviewed journals (Turpin, Barley, Beail, Scaife, Slade, Smith and Walsh, 1997). Turpin et al. (1997) indicate that samples less than 5 would be unacceptable unless exceptional circumstances, such as difficulties in accessing the sample were encountered. Turpin et al. also report that many journals publish qualitative studies with between eight and twenty participants. Research has been published in this area using as few as four participants (Midence & O’Neill, 1999). Elliott, Fisher and Rennie (1999) in a much cited article outlining guidelines for doctorate level qualitative research, do not mention minimum sample sizes as they are not central to the issue of defining quality in qualitative research (see Credibility Checks).

Interview Schedule:
Following the epistemological position of the study and research questions, a semi-structured interview schedule was designed. This form of interview is especially suited to IPA analyses (Smith, 1995) and was also chosen as it facilitates rapport with participants thus helping the researcher to get closer to an insider’s perspective on the
material. Semi-structured interviews can also reflect participants’ own concerns whether predicted by the researcher or not, thus allowing unexpected findings to emerge. Thirdly they allow for the exploration of both complexity and ambiguity in participants’ positions (Smith, 1995). A selection of questions from the interview schedule are listed below to give an overview of the areas covered (Appendix 1).

A) What challenges has being the father of a child with an autistic disorder confronted you with?

B) How have you made sense of the challenges which caring for your son / daughter has raised?

C) How do you consider the role / challenges / position of a father of an autistic child to be different from other family members?

D) What kinds of support have you asked for during the first few years of caring for your child?

E) How would you summarise your experience of the process of assessment and diagnosis of your child?

During the interviews participants were asked the questions on the schedule (Appendix 1). Primary questions, using the wording discussed below (Reflexivity and Critical Language Awareness) were given in order to structure the interviews. Secondary questioning, at my discretion, followed responses to the primary questions. Secondary questioning aimed to clarify, extend or further explore a participant’s position. The aim was to use open questions and vocabulary previously used by the participant, so as not to constrain their further responses (Smith, 1995).

Procedure:
The interviews lasted for 60 to 75 minutes each and were conducted by the researcher. The majority took place in participants’ homes. Using semi-structured interviews in the fathers’ homes was consistent with attempting to remain grounded in individual accounts and interpreting these within their individual contexts. Each interview started with an introduction to the study, covering the points made on the information sheet and consent form (Appendices 2 & 3). The consent form was then completed.
Interviews were audio-taped, transcribed and the tapes destroyed by the researcher. Upon transcription, personal and service names were altered to preserve anonymity. Any unusual personal information which could have identified individuals was also altered. This was a particular concern due to the sample size, the single-service recruitment strategy and the homogeneity of the sample. Eight transcripts ranging from 18 to 35 pages of 1½ line-spaced text each, formed the data on which the analysis was performed. One transcript is included in Appendix 5 as an example.

Process of Analysis:
The transcribed interviews were analysed using Interpretative Phenomenological Analysis [IPA] as described by Smith, Jarman and Osborn (1999) and with reference to Willig (2001). IPA was chosen as the method of analysis as it would complement the aims of the study. An idiographic form of analysis was undertaken. Thus, each transcript was initially analysed on its own and any emerging themes within the single transcript were noted. After that, the next transcript was analysed. As the analysis developed, the emergence of themes across transcripts was noted and themes were reconsidered, merged, deleted or rearranged, eventually to encompass all of the transcripts. In this way the emerging themes moved from being based on a single transcript and being relatively descriptive, to reflecting something about several or all the transcripts and being more interpretative. The final interpretative analysis as presented in the Results and Analysis section, is the result of several iterations of the process of combining, rearranging and re-interpreting themes within each case and across cases.

Throughout the text, quotations are cited in the following form: (Participant: Page Number. Line Number). For example (Mark: 12.27) refers to a quotation from the interview with participant Mark, page 12 beginning on line 27.

Reflexivity and Critical Language Awareness:
In this section I (the researcher) discuss my own position in relation to the data and hence the influence of this on the interpretative account given later. At the time of the research I was 30 years old, a white male U.K. resident and recently married with no
children. My clinical interests lay within Child and Family Clinical Psychology services, in particular around the areas of disability, chronic illness and developmental disorders. My primary interest in conducting the research was to let the voice of the participant group be heard. This voice in my view had previously been under-represented in the psychological literature (Introduction). Further, my interest was in the area of father's definitions of challenges, their definitions of what they had done in response and how they felt their gender related to these.

Because the aims of the study were to discover and explore participants' own definitions of challenge and response in their terms, it was decided to alter some of the language used in early drafts of the interview schedule. This would be described as a process of critical language awareness (Willig, 2001). To give an example, in the interview schedule the terms “challenge” and “response” were put in place of the terms “stress” and “coping”. This was done in order to avoid bringing in psychological concepts which might limit fathers’ constructions of challenge, or bias their responses toward lay-psychological constructions of stress and coping.

**Credibility Checks:**

Although many traditional criteria are inappropriate for qualitative research, based as they are on quantitative concerns, Elliott et al. (1999) discuss credibility checks which can be appropriately applied to qualitative studies. They call for researchers to check their interpretative analysis against that of other informed parties.

At an early stage (after one interview had been initially analysed) a group of colleagues who participated in a qualitative supervision group, read and commented on the transcript. These colleagues were similarly educated but of mixed gender, age and background. They suggested their own interpretations of the data and ideas for emerging themes. This was a useful process which allowed me to compare the draft analysis to that of other informed parties and to check for comprehensiveness, accuracy and to judge my own bias in relation to the data.

Throughout the study the researcher underwent regular supervision from an academic supervisor and a clinical supervisor (attached to the Autism Assessment Nursery).
Supervision also functioned as a credibility check, in that it provided another perspective on the proceeding analysis and offered new or different interpretations of some of the emerging themes or their relationships.

A further credibility check was conducted as an integral part of the method. This used the previous participants’ insider perspective to inform subsequent interviews. At the end of each interview, the participants were asked whether they felt that the researcher’s questions had covered all the areas of interest or concern. Participants’ responses were then considered and some were included in subsequent interviews. For example, Phil suggested that “strain on the marriage” (Phil: 36.27) be asked about directly. In subsequent interviews an extra question was added by the researcher on this topic if it had not been discussed spontaneously.

**Research Questions:**

Research questions were generated after discussion with supervisors and a review of the literature in the areas of fathers of children with autism, fatherhood and parental stress (see Introduction and Gentil, 2001). The research questions were worded to reflect the aims of the study and followed the guidance of Smith (1995) and of Willig (2001). They were written to allow the research to follow closely from the participants’ understanding, without constraining the participants’ responses to fit with existing psychological concepts and also to allow for the generation of unexpected findings, ambiguity and complexity. The research questions were;

1) *How do fathers define the challenges of parenting a child with an ASD?*

2) *How do fathers respond to the challenges of being father to a child with an ASD?*

3) *How do fathers experience the current services for their children?*
Analysis and Results

This section contains an account of selected themes. Selection of themes was necessary due to the large amount of data generated. Themes were grouped to speak about (1) Challenges, (2) Responses and (3) Unexpected findings out-with these categories.

Section 1: Challenges.

Fathers’ constructions included challenges arising from the process of diagnosis, the label of autism, their attributions/appraisals of the characteristics of autistic children and their behaviour, personal/emotional challenges, practical and time-based challenges, challenges for the couple and their relationship and those arising from the educational system.

The Process of Diagnosis:

Evolution and shock emerged as a theme from fathers’ accounts of the process of diagnosis and their feelings throughout it. Phil describes how for him there was an evolution from short-term medical concerns to the shock and realisation that the diagnosis of autism was a life-long thing “I think the diagnosis is like a bolt hit you, it’s a very heavy thing. This is not your kid’s got conjunctivitis, I’ll give him some ointment and it’ll go away, I mean this is a life-long thing. And he’s probably likely, he or she, to go and read about some things. The medics try to drip feed you, try to break it to you, and I don’t like that. It was right for my wife I think. But I don’t like it, get to the point doc, I’m a big boy, I can take it and then when it comes it’s like whoh, jeez, that was heavy. Um. But, when that lands on you, you may go off and read something. And then ‘cos they haven’t told him this is a life-long thing, you read it’s life-long and it sticks out and flashes at you. And then, whoh jeez, what can I do? Does this mean that when I’m sixty-five I’m still gonna have this kid living with me and all the rest of it? So I think that when that diagnosis lands, its, you need the most support. (Pause).” (Phil: 30.22). This passage also shows one of Phil’s major habitual responses, ‘Research’ (Section 2).
Phil was one of the fathers whose children had initially been investigated and / or treated for hearing difficulties, "and I think he [audiologist] was probably the first one that alerted us to the fact that things weren't going exactly to plan. Um, that Bob could turn his hearing on and off effectively. Decide to react if he wanted to, and wouldn't if he didn't." (Phil: 26.25). Mark, who shared a similar experience in his child's assessment, said of the assessment process "it sort of evolved" (Mark: 21.24).

The evolution from a suspected treatable medical condition to a lifelong condition with no cure or clear aetiology emerged as a strong theme within several fathers' experience of the assessment process. "... a quick hurdle, it's not glue ear, it's not hearing aid, it's suddenly something that's going to be with him for the rest of his life" (Steve: 7.2). Mark's relief that his concerns, which had developed through an evolutionary process, were justified was evident "the fact that my wife and I talk about these things, and we tried to analyse what had happened to us and our children, meant that we were already there, that there was a problem with our second son before the health professionals got into it. It was almost like a relief to find what it was, and what can we do to help and to focus on something else." (Mark: 24.28).

This evolutionary process from short-term medical concern to life-long diagnosis comes about not only because of the pattern of assessments carried out, but also because as Mark describes in humorous terms, fathers are naturally invested in their children not having something serious to deal with, "You know, it's like you buy a new car and you don't sit there and think, actually that's crap. You give it the benefit of the doubt, someone says that knock's not right, you go nah, it's shiny! I mean you don't invest much emotionally in a car, but with a child it's so hard to hold them up and say that that child isn't right in some way. This child is your child, it's yours, and what you want if there is a problem is like an in-growing toenail, you want your child back fixed." (Mark: 20.10)

Fathers are therefore invested in there being a benign answer for the difficulties their children present and only when the investigation of simple causes fails does the process evolve into looking at developmental disorders with their life-long implications. The pace of professional assessments compared to the pace of fathers' knowledge development and meaning-making around this are therefore likely to be important
factors in whether shock is experienced when the diagnosis is finally made or whether relief is experienced instead.

*Autism and the Label of Autism:*

Once a diagnosis of autism is made, challenges may arise from different sources. Such a challenge relates to back to the uncertainty felt throughout assessment. This is the challenge fathers face in coming to terms with label of autism itself. Autism was described as being “a big label, a big label” (Paul: 12.8). In common with several other fathers, Colin describes how he came to understand the spectrum by reference to autistic children who he encountered personally, because no professional had “ever told us where, on the spectrum she is” (Colin: 1.18). “Um, well, we know what the spectrum is ‘cos we’ve been to [School A] and we’ve been to [School B] to look at the different types of children that are on the spectrum, so we can see how wide the spectrum can actually be.” (Colin: 1.24). Henry describes the ends of the spectrum as he sees them as ranging from “like dyslexia . . . just an inconvenience” (Henry: 6.24) to those children that “can’t get on by themselves at all” (Henry: 6.27). All of the fathers in the sample showed an understanding that autism is not a discrete state, but is best described as a spectrum within which their children fall. Participants also highlighted the importance of understanding autistic children’s widely differing individual needs. Advice to other hypothetical parents included “try to get them to think not of the label, but what are the strengths that they can work on, ‘cos that label, the label’s this long, and yours might only be a piece of it, somewhere along there. So you’ve got to work out what the strengths of that kid are, and sort of bring them on” (Phil: 31.4).

*Social Judgements:*

The challenge arising from negative social judgements of the parent and the child was evident before and after the diagnosis. Firstly fathers described how they felt that people judged their children’s behaviour unfairly “because the children look normal I don’t think everyone really understands that the condition is in the brain or whatever and they think that the child is just normal or is just a badly behaved child, um, causing a few problems, being badly behaved.” (Paul: 10.5).
Secondly, some fathers felt that this reflected directly on them, "they just think it's just a very badly behaved child. What are those parents doing!" (Paul: 11.32). Colin similarly explains, "and you don't judge a child on what it does, you're judging the parent at that point, because it's not up to the child to know what to do, it's up to the parents to have told the child what they should be doing. And um, it's like um, it's never a poor student it's only ever a poor teacher isn't it!" (Colin: 17.7). This source of challenge emerged from an interaction between the children's behaviour and the fathers' personalities and attitudes. Some of the fathers who described their child's very unusual behaviour in public were less affected by this challenge than those who were concerned about slightly unusual behaviour. Fathers who were affected by this challenge were more concerned about other people "you don't want to ruin everyone else's meal, so you have to go" (Steve: 14.11). However, by no means all the fathers found this challenging, "I don't worry about it," (Mark: 15.23), "they can understand or . . . tough, 'cos we're not going anywhere" (Paul: 10.5).

Uncertainty:
Uncertainty emerged as a personal / emotional challenge in some of the fathers' experiences. Colin, felt that uncertainty was engendered by the autistic spectrum itself, "She's on that spectrum somewhere, but no-one has ever told us where, on that spectrum she is." (Colin: 1.18). Ivan felt that uncertainty was a particular challenge for him before a diagnosis was reached "not knowing whether it is autism or not can be very taxing, a diagnosis will end your mental agony" (P7: 23:10). He related this to the fact that his job at the time meant that he was alone and reflecting on his concerns for his son for hours without social support or contact with his wife.

Uncertainty was also an aspect of behavioural challenge, being related to the child's behaviour from day to day, which was described as being "complete randomness" (Phil: 38.19). He described this as being a particular feature of autism, "... a child who's not autistic, you can usually see things building. You can see it coming, and you can either deflect their attention, divert their attention, nip it in the bud, ... with an autistic child it comes right out of the blue (snaps fingers). And you don't know what's triggered it" (Phil: 4.16).
Phil also felt that uncertainty characterised autistic children's longer term developmental progress, "the child we have today may make great progress along a particular path, but in two years time he might take a completely different turn, I mean he could develop epilepsy, that's one thing, he could just reach his learning capacity and stop, or he could shoot up and be a genius, each one with its own set of challenges. Um, and that is, probably confined to autism." (Phil: 38.20). Although uncertainty was not linked explicitly by fathers to difficult emotions, it was interpreted that it tied together several of the challenges reported.

Uncertainty also emerged for some fathers as being related to service provision, "... in the early days it was two afternoons a week and oh, um, yeah, you can have another one then ... all very very vague." (Colin: 24.4). Thus uncertainty was also a factor in the practical challenges of parenting for Colin as it necessitated him having to alter his working pattern and the family's care arrangements at short notice.

**Time Stress:**

Many of the fathers reported feeling under time pressure or that they had too many competing demands as a result of their child's needs. For example, the peak stress time for Phil was when he was forced to commute weekly several hundred miles in order to earn enough money to support his family during the process of diagnosis of his son. He described how this was a practical and an emotional challenge. The emotional challenge came from his feelings of being out of control, and unable to support his wife "'cos you're out of control, you can't reach it. So I started coming home mid-week as well." (Phil: 23.10).

Steve used the phrase "time stress" (Steve: 2.18) to sum up what was the biggest challenge for him. For him the difficulties faced always had a time component. There was never enough time, always many things competing for his time and this left him feeling tired and stressed. Steve felt this had negatively impacted on his work performance and this had therefore became another source of concern for him "if you're tired and a bit cut off then you can't think the way you need to to get the job done right, and that becomes another problem" (Steve: 25.15).
Colin talked about the time and effort required by both parents to adjust to the demands of caring for an autistic child “... at that point between the age of two and three was a time when we, a lot of time was needed to be spent trying to understand what we had to do as parents, to try to understand what we had to do to help her, what [County] was going to do to help her, it took an awful lot of time up, and it was apparent that that wasn’t going to abate probably for another five to six years.” (Colin: 11.18).

Mark also felt that time was an important factor in the challenges presented by autistic children. He described the tiring and time consuming process of communicating with his son. “You either have to accept that he's going to cry all day or spend a lot of time figuring out what it is that he wants. But it can be quite frustrating ... it can be a long day to find out what he actually wants.” (Mark: 4.2). Mark was one of the fathers who went on to discuss how developing patience was a personal challenge, as described below.

Henry felt that as a father of an autistic child, the need to be patient all the time constituted a “personal pressure” (Henry: 2.25). Patience was required because of a lack of co-operation on the part of the autistic child and “so often you do just want to explode, particularly when the behaviour, they’re not coming, they’re just sitting there” (Henry: 2.20). For Henry this could be achieved in this way, “you have to remember the lectures you’ve had and actually focus on the issue, you know he fixates on things, like his video and he has to have it” (Henry: 2.22).

Paul also described patience as an important trait in fathers of autistic children, and linked it with the everyday pressures which parents face, “it must be difficult for people with financial problems, things like that, other problems outside all this, other things taking their minds off what’s going on with the child, then you can’t have the patience.” (Paul: 19.2). For Paul, being patient was not something that can be performed uniformly but that its expression can be threatened by the presence of other everyday pressures.
Strain on Parents’ Relationship:
As well as time pressures, strain on the parental relationship was initially raised by Phil when asked at the end of his interview whether there were any areas which had not covered. “I might have expected you to ask about how it’s effected our marriage bond. And in ours it created a, there was definite tension in that this was something we had to learn to cope with. I had my way of dealing with it and Julia had hers, and they weren’t together, um, mine was to learn as much as I could about it and Julia’s was to wait and see what people told her.” (Phil: 37.6). Ivan in contrast did not report marital strain. He described how “my wife deals with the day to day care, and my role is more about how he will live in the future, what he can achieve” (Ivan: 14.10). The clarity of roles between him and his wife seemed to be an important factor in the robustness of their marital relationship. Role definitions are discussed further in the Responses section.

Sadness and Responsibility:
Many fathers’ descriptions of challenges contained experiences of difficult emotions such as loss and responsibility. Feelings of loss were centred on the loss of an imagined ‘normal’ fatherhood, “it’s what people imagine having a child is going to be like, and realising that that’s not what it’s going to be.” (Henry: 8.15). Henry also indicated loss in reflecting that “it’s always in the background, in quiet moments you sometimes think I wish it wasn’t like this, it is there.” (Henry: 7.10).

Phil’s denial of sadness over the fact that his son was not ‘normal’, whilst indicating that these difficult emotions had been felt, shows how some fathers keenly felt the vulnerability of their children “And I don’t... it doesn’t hurt me that he’s not... quite like the others. It doesn’t hurt me that way. I just feel he needs a bit more help. And I just feel more protective toward him (said with great fondness).” (Phil: 8.28). Parental feelings of responsibility for their children’s welfare and development were a feature of many of the fathers’ accounts of their actions. Beliefs about the implications of their actions and decisions was clear, “and so if you haven’t got the ability or the where with all to sit down for the whole of a Sunday then your child could end up at
the wrong school, or get the wrong help, or maybe no help what so ever.” (Mark: 12.27).

Mark, a businessman, felt that a challenge derived from parents’ responsibility to access the best services for their children. This challenge hinged on professionals’ reactions to fathers’ presence, and hence the presentation of the parents as a couple, “I turned up at the reviews, and on the first one someone said oh it’s nice to see the father here, or something like that. Said in a nice way, but it’s like what the reverse of that? Oh, is there a father available? Could he be bothered to turn up? I also make the effort to turn up in a collar and tie ‘cos I think you get a better . . . performance there, if you say hang on you used a bit of jargon that I didn’t get, could you explain that, and if you have notepad available. And I happen to think you get a better service if you present yourselves together as intelligent people who are hear to actually listen, and debate properly about the future of your son,” (Mark: 23.2)

Fathers’ feelings of responsibility did not just centre on protecting their children, or accessing the best educational services for them, but also on providing them with the optimal environment in which to thrive. For Steve, this was highlighted by the recent development of skills in communication after input from a Speech and Language Therapist “And for three months I was just listening to my child say look and he was actually saying oi look thicko tell me what the word is! You know if we’d known that back then we could have helped our son.” (Steve: 18.6). Colin also reported this challenge, “…she gave us one of the best bits of advice that you could ever give, ‘cos there were lots of people there saying, ‘my child needs speech therapy!’, and she said how ‘now is a speech therapy’, and the truth is . . . they need it twenty-four hours a day, and the only persons that are going to give them that is us, as the parents. And the challenge to us is to learn how to teach them.” (Colin: 5.20)

Services:
Phil also describes the challenge arising from the educational system and his feelings of responsibility, “But there’s no question that the stresses and strains of the education process, our current worry is will he get into [School] which we believe is absolutely the right place for him. Will he get in when they only have 8 places a year and you’re
competing with everyone in the county. It’s a worry, that causes, it’s just background noise you don’t need really. And it’s just, I think a lot of people’s marriages would be very strained by that.” (Phil: 37.20). Indicating similar concerns, Henry expressed a wish for more guidance about appropriate educational placement from both health and educational staff, “Professionals . . . can be either very helpful or rather superficial, there are some things like picking schools, where there seems to be some kind of restriction and nobody can say whether that school’s a good one, that’s not, but you want pointers, I mean we don’t know, but you find with the schools they’ll say we can recommend a certain number of schools or show you them, but we can’t recommend which one he should go to . . . so support wise from that, it hasn’t really been sufficient” (Henry: 13.17)

Another challenge which arose from fathers’ constructions of services, was the weightiness of “the system” (Colin: 29.23; Mark: 12.4) especially around the time of parents’ first concerns. “The only time I felt the system let us down was the 5 months we had to wait to get her into the service after the diagnosis which I felt was a wasted 5 months. She should have been there, we went to the school several times, the place was there, why on earth wasn’t she there, that’s exactly what the staff at [Autism Assessment Nursery] were saying.” (Colin: 29.18). As Mark humorously observed in his new car analogy, fathers described how everyone in the system is invested in the child not having a serious problem. This includes, the parents, their families, and the professionals currently involved with the child. The large amount and the complexity of paperwork which some parents were faced with (or felt they needed to be actively involved in) as part of the educational statementing process, also contributed to this feeling of weightiness “there’s a lot of paperwork, you don’t realise how much paperwork there is having a child that’s got contact with the system” (Mark: 12.3).

Summary:
The process of diagnosis emerged as being a weighty construction which fathers felt needed proactive parental input and which involved significant uncertainty. The process was seen as evolving from parental concerns through medical investigations to specialist service assessments. The autism diagnosis’s power was largely in its ‘lifelong’ implications. To some fathers the diagnosis was primarily a shock, to others
it was a confirmation of what they thought beforehand. The label of autism still had great power, even for those for whom it was a confirmation. Fathers reported difficult emotions including heightened responsibility derived from their perceptions of the increased vulnerability of their children. Participants also noted strains on the marital relationship and that this could result from incompatible coping strategies between the parents.

Section 2: Fathers' Responses.

Changes in Attitude and Perspective:
In response to their experiences fathers described how changes in their personal attitudes had occurred. A change in perspective with regard to work was backed up by changes in several fathers' work patterns or job choices (Ivan, Colin, Henry, Mark)

"it has changed my perspective, um, there are more things in life than work. If I do a job I like to do it well. And I'll still take it seriously, but . . I also want more time at home than previous jobs have allowed. You get paid a good salary, but then, there's a pay-back for that, they expect a lot from you. And I'm probably at the point now that I don't want to give, . . that kind of commitment to another job, because I enjoy watching him grow and develop." (Phil: 9.26).

Mark similarly reported a change in the importance of work, "when I'm sitting with them in the pub at 18 hopefully, I won't remember the important meeting, or even the names of the people that would have been there, but my lads will still be there. That's what becomes important" (Mark: 27.24). But he believed this was essentially about being a father, not the father of an autistic child, "It's about me as a parent because I would do the same for all my kids." (Mark: 27.21).

Changes in perspective were also centred on father's personal expectations for themselves, "your expectations for your family are higher but your expectations for yourself are lower" (Mark: 26.1). "Your forced to put your selfish bits to one side" (Mark: 26.9). Paul reported how a change in his thinking around disability had resulted from his experiences, "it's made me respect all sorts of disabilities now, deafness, blindness, whatever, you start to think about how people out there are suffering with these disabilities." (Paul: 6.5).
Phil described personal changes which had positively affected his social relationships arising from his experiences, "Through this process of learning about autism and not . . . being careful about what you say to other people, and being more circumspect in general, I'm much less likely to offend people by saying something straight off the bat. I'm much more thoughtful before I say something." (Phil: 12.11). Phil who reported being easily embarrassed when younger, also described how as a result of his experiences of caring for his son who could be challenging in public, that now 
“I don’t care about crowds, or what other people think. So I’m much more, I’m much less inhibited in fact, as a result, so it’s done some good there.” (Phil. 11.12). This can be seen to be an important change for him, as negative social judgements are a feature of fathers’ experiences and would be exacerbated by his earlier perspective.

Uses for the Label of Autism:
Fathers responded to the challenge of the diagnosis of autism by seeing the label of autism as something that had its uses. The utility of the diagnosis was uppermost in Colin’s mind as he described his thoughts at the very point of his child’s diagnosis as being, “yup, now what are you gonna do for me?” (Colin: 25.13). The diagnosis or label of autism was seen by several fathers as a double-edged sword, in that their child might be labelled (a bad thing) but only then would they be given appropriate help to address their needs (a good thing). “And that’s when I had to confront on a personal level having a child which someone is going to put a label on . . . now afterwards when my wife was reacting like that I was like hang on, Andrew wants help, if we went to the meeting and they said there’s nothing wrong with Andrew, we can’t help him he’s perfectly normal, then we’d have been up in arms writing letters saying well there is something wrong with him, our son is not talking, he’s not communicating with us, so you can’t have it both ways, you can’t have the help and then have people say you’re child is special but special for the wrong reasons.” (Mark: 6.25)

The benefits of having a diagnosis were often discussed. For example, “When she told me, Dr. [Paediatrician], that said he was autistic . . . I was kind of upset, but thought OK, well now we know what we’ve gotta deal with.” (Phil: 21.18). Similarly Phil describes how “I think the other thing is we like to put labels on things ‘cos it gives an
order and it gives a reason” (Phil: 31.4). It was interpreted from these and similar comments that a diagnosis was important as it helped to reduce uncertainty (underlying several challenges defined earlier) and to enable fathers to respond by making sense of how their child behaves to some extent. But as Henry noted, despite the utility of a diagnostic label, other practical concerns are of more urgency for some fathers. “. . .they say it’s good for the person themselves to have a label when they get older, why they do certain things, but the quick diagnosis, you know you’ve got the label, that’s what’s wrong with him, you know what you have to do, there’s something identifiable, and you could sit down and worry about it, but there’s so much to do.” (Henry: 6.8).

Participants also constructed the autism label as something used by fathers as a response to and hence a defence against, negative social judgements “I mean I don’t think people are judging the child, I think they are judging the parent. And, the number of times you end up saying “She’s autistic”, (laughs), totally wrong, but you do.” (Colin: 17.32). Likewise, Paul says how he dealt with this; “we’d happily explain that he’s autistic and that’s the thing that he sometimes does and that you can either try and understand that or go away ‘cos we aren’t going anywhere!” (Paul:11.3).

Mark however, was less happy to use the label of autism as an explanation or as a defence preferring to keep it hidden and not wear it “like a badge” (Mark: 7.30). His response was to describe his son to people who were not close to him, in more neutral terms, “oh sometimes he gets a bit difficult but he’s faster at other stuff you know.” (Mark: 8.1).

Researching:
Participants also noted some specific and concrete responses which included researching autism. This theme formed one of the clearest personal coping responses to fathers’ experiences. For many, reading, watching documentaries and accessing the Internet for information about autism was a significant response to the concerns for their child, “my being able to explain from having read, is therapy in itself.” (Ivan: 18.6), “The Internet I think, thousands of sites, even back then and they gave the classifications and descriptions” (Steve: 15.26). “He first started to be delayed with
his speech. And I looked up reasons for delayed speech, and autism kept coming up, and I dug deeper into autism, and I learned about it, and that's really how I... how I began to cope with what was coming up. Preparing myself, learning about it. Um, looking at worse case scenarios, looking at best case scenarios. That sort of thing.” (Phil: 6.29). Fathers also mentioned this response as part of the advice they would give to a hypothetical father at an early stage of the assessment process. Participants differed on exactly what they wanted from professionals in this regard. Some fathers had already armed themselves with web-based or book learned information about techniques etc., by the time of diagnosis and wanted practical or contextual advice “the sort of stuff that isn't in the books, isn't on the web” (Colin: 33.10). Others had not yet gathered this information and wanted “information passing” (Phil: 33.4). This highlights that responses and thus needs of fathers around the time of diagnosis vary markedly.

Roles:
Role construction emerged as a response in the latter stages of the analysis. Initially, many different gender and parental roles emerged as individual themes, from traditional breadwinner roles, to heavily increased father involvement and care-sharing, especially around the interaction with services. None of these different patterns seemed to necessarily result in better adaptation or less reported stress. As the analysis continued these different role patterns were interpreted as being illustrations of the encompassing theme of role construction as presented here. The major finding was the flexibility that fathers described in the couple’s sharing and adjustment of roles in order to meet the needs of all of their children including non-autistic siblings. This included Ivan, whose family tradition was of well-defined breadwinner and caretaker gender roles, but who had made a substantial change to his working life (change of job type and location) and was now becoming more involved with the everyday care of his son.

The first illustrations of role flexibility were examples where both parents shared the same role. For Phil this was in interpreting for their child in interaction with others. “So it would be the interpreter. And my wife would do it with her own family, just because they are closer. I would do it if I’m there, but I think it’s interpreting what
we know him, we know what his expressions and his movements mean. And we can pass that on.” (Phil: 16.29).

Role flexibility was also illustrated by changes in the couple’s roles with respect to their individual children and to the way that discipline and boundaries were constructed for children (being different with non-autistic siblings). Colin described how the couple’s roles were the same with their autistic child (Chelsea), but different with her non-autistic sibling (Joanna). “I have a far different role with Joanna than Sue does with Joanna, but I don’t feel that’s the same for Chelsea, I feel we have the same role, mainly ‘cos it’s the . . . I’m getting back to the routine and the way things are done, everyone has to do the same, or you’re giving her the wrong messages, or that’s what we try and do in any case. So I don’t feel my role is any different, only the fact that I do the baths all the time, and, or, I do this, it’s just a matter of timing or convenience, but I wouldn’t call those . . . practical differences. But I’d say that I do deal, I deal with Joanna differently than Sue deals with Joanna.” (Colin: 18.17). This view that parental roles were different between autistic and non-autistic siblings was not held by all fathers though.

Some fathers described their unique role as being the disciplinarian, in this case for both autistic and non-autistic siblings, “Mum’s still mum, the soft one, I’m the one who you muck about with or get told off by, which is a bit unfair being in that role, but it has to be like that, and it’s the same with Jemima, it is the same.” (Henry: 11.31). Conversely Steve felt that he was the opposite and defined himself as being in the less disciplinary role, “My wife is more of the disciplinarian and I’m more of the softer touch with him. And it’s different in that sense.” (Steve: 10.16)

Some participants described a breadwinner role as being the most salient or unique role, “it’s making provision, that’s my role, making provision so that he can be as self-sufficient as he can be without uh being a burden in inverted commas on our other children. So that is the way I look at it in that I’m trying to make as much provision as possible for him . . . I think that’s where the roles are a little bit different.” (Paul: 12.18); “my wife deals with the day to day things, and my role is
more about how he will live, what future he has and what he can achieve, how he can be integrated into mainstream society, the longer terms things” (Ivan: 28.15).

Fathers including Henry and Colin also described their unique role as turning on the ability or willingness to use physical interventions and play, “One of the things is the physical strength. Strange thing to say I suppose, but um. There are just occasions when getting him out of the car, when he doesn’t want to come out of the car, when he’s got all arms out and legs out and gone stiff as a board, there’s a physical strength thing.” (Phil: 16.11)

Phil talked about how a problem solving approach was one of the characteristics of fathers’ approach to challenges, “But as I say, um, not all men are the same, but in general I think we tend to be problem solvers, research and analyse, and come up with an answer, whether you’re a chippy or a brain-surgeon, it tends to be the way men attack things.” (Phil: 22.19). This was also reflected in Colin, Ivan and Steve’s accounts, with fathers positioning themselves as having strengths in objective problem solving, especially at difficult times when their partners were struggling to cope with the emotional impact of their children’s diagnoses.

The process by which role definition came about hinged on a mixture of practical, characterological and cultural factors. Colin gave the clearest examples of all three groups of factors. He talked in terms of what needed to be done “They’re just practical differences” (Colin: 30), what he was like as a person “Only from character traits” (Colin: 20.1), or what he accepted as culturally defined fathering roles “it’s like this old business, oh I’ll tell your father you did that” (Colin: 19.3) and none of these factors seemed more strongly represented than the others in the participants’ accounts. As previously described, Ivan’s family’s traditional role definitions were being reconsidered in the light of the practical necessities of their new situation. Similarly with the other fathers, all three groups of factors were present in their role descriptions and role choices.
Problem Focus:
In many accounts there was an underlying theme attributed to fathers or men. Fathers accounts contained many examples of a belief that action or problem solving (or ‘doing’) had primacy over emotional processing (or ‘thinking’) “If you get hung up on his problems, you’ll find it harder to cope” (Phil: 19.23). This theme emerged firstly with fathers’ descriptions of themselves as being problem-solvers, “I think I’m just too busy solving the problems.” (Colin: 9.16), and was then widened as new examples were given, “He’s Bob and that’s it. That’s the way he is.” (Phil: 19.30), “it’s an acceptance that this is the problem, I don’t think I’ve sat down and over analysed it, um... I just accept that this is what it is, and move on.” (Henry: 5.26).

Action was given precedence over thinking because of the necessity that problems had to be solved and behaviours managed, but also there was the suggestion that analysing too much was a bad thing in itself “I think if I do sit down it would make it worse, but as I say it’s not that bad. If you sit and think too much you’d tie yourself up in knots. I mean he’s a happy kid in himself... maybe that’s just me, I just go with the flow, if I overanalysed it I would go and... it could well get worse, my feelings toward Jimmy might get worse...” (Henry: 5.30).

Mark, Henry and Phil felt that their partners at times had thought too much about things, and that this led them toward feelings of depression. This was most strongly reported during periods of separation due to work arrangements. Thinking however was not exclusively seen as a bad thing. In fact some fathers described analysing as a tool to be used toward the greater goal of problem solving. “And if you can look at where his strengths are, and where he’s making progress, that does a lot.” (Phil: 19.24). Coping by not over-analysing or being drawn by the difficult emotions described previously, seemed to be something that happened without participants being able to identify how it was achieved, “But I mean sometimes we just sit there and think... God how are we going to cope with it all, but you just do you just seem to get on with it. And even through his bad times we um... just take a deep breath stick our heads down and get on with it. I mean it’s, I don’t think we ever sit down at the end of a week and think can’t cope with this any more, we just get on with it.” (Paul: 4.1).
Work:
Participants discussed how they had responded to the challenge presented by their children's needs by making changes to work arrangements, social lives and family activities. These changes hinged more on practicalities, their solutions to problems and the limitations of families' personal, financial and social resources. Fathers reported value of a flexible work situation. Fathers who reported less difficulty around work were those that were self-employed or felt that they had some flexibility in their working hours. As Colin describes, he turned down a promotion in order to retain the flexibility that his present job allowed him, “I work in job which is very flexible and if I didn’t work there then I’m certain that my wife would not be able to work, having Chelsea. Because, the amount of things that you have to do to pick her up from places and to get her off to places and attend . . . reviews, boards, all sorts of things, if Sue had to all of those then she would not be able to work, so I’m lucky from that perspective that I’ve got a job that if I want to go off at ten in the morning for an hour for an interview I can . . . so from that point of view the only thing is that a few years ago I did look at changing my job and because Chelsea was Chelsea that was stopped, we decided we could last on the money we’ve got and we’ll put up with whatever we’ve got to.” (Colin: 10.24)

Those that had more traditional nine-to-five jobs reported more difficulty with their working lives. For Steve this related to his child’s short and unpredictable sleep cycle “that’s the problem, you get up at 5am ‘cos of David and you go to work tired, and that makes it difficult to work properly” (Steve: 6.8). For Colin, the provision of school transport for his child meant that he could continue to work full-time and his wife could start part-time, “Cos now Chelsea goes on a bus and the bus doesn’t arrive home until quarter to 4, and Sue can pick up Joanna and be ready for the other one to come home” (Colin: 12.21). Mark points out that his position, role within the family and choices around working hours was only possible due to their socio-economic status, “We had the idea that if we were going to have children then my wife would give up work anyway, and that’s O.K. and we’re lucky we’ve got the economic circumstances where we can just about afford to do that. You know we only run one car, we only do certain things, you make certain sacrifices, but we have a reasonable
standard of living, but we’re lucky that we can do that.” (Mark: 11.19). This was likely to be true for the majority of fathers in the sample.

Social Lives:
Fathers’ responses in terms of changes to their social lives were mixed. For several fathers it was a major source of change. “We’ve never been away and left the kids before” (Colin: 15.20), “that’s gone down a lot” (Steve: 7.9), “he’s like a spinning top sometimes, and the place can look like a complete bombsite when he’s been through it and you can have someone coming round for a meal on a Saturday and he can, well . . . not ruin it, but be a real pain” (Paul: 3.29). These changes often related to the time or difficulties in taking the child to other people’s houses, or leaving them with other people, which could well be thought of as a challenge in its own right. “We have real problems with that . . . real problems. We have a large circle of friends who are very good but we feel much happier when we are at home. The house is Chelsea proof. If she breaks anything then that’s our fault. If we went to friends houses . . . what we did was, when you went out was . . . follow her round for the entire time which is not what you’re going to see friends for.” (Colin: 12.29).

Phil, when asked about whether such a change had been necessary, replied, “No, I don’t think so. I don’t think so” (Phil: 11.27). He, along with several other fathers, answered the question in reference to the social life of both themselves and their partners, not distinguishing between the two. Many fathers also mentioned that they did not socialise with people from work, “I don’t really socialise with people from work, not outside work. I haven’t shared David’s problems with them. But then I don’t think they share their problems either. I think some of them know. But they don’t talk about it. It’s one of those things that it’s like a different world and you go in that world as a worker, not as an autistic father, like there’s a chap whose daughter has an eating disorder, but he doesn’t talk about it.” (Steve: 6.26). Interestingly, the fathers interviewed talked very little about any social activity that did not involve either their partner or their children, which was what the question aimed to explore originally.
Family Activities:
With regard to changes made to family activities, some participants discussed how holidays were altered in terms of what was done, "Well, we might have ventured abroad and things like that, but with Chelsea we just couldn't at this moment in time" (Colin: 14.5) and also in their frequency and length, "we try and take a lot of short but lots of them, breaks . . . but we've found they're very good for her" (Colin: 13.30). For Colin, this change was due to previous bad experience of trips away, "so you can imagine, at night, every time you heard a bit of noise you thought "is that Chelsea getting out of the caravan?!", we went home two days early, 'cos we just weren't enjoying the holiday and we were absolutely dead beat" (Colin: 14.20). Not all families made such changes however and those that did not, seemed to have made a clear decision not to do so, "but we've never said oh no we won't take him to a restaurant or a public place 'cos he might get the screaming ab-dabs, as long as you prepare him properly, sit him down and say we're going to a restaurant today, we'll take your toys, he has a little back pack and he takes his special toys, and as long as he's prepared there's no problem" (Mark: 9.23).

Paul similarly felt in a position to be able to take risks and find whether holidays were possible or not, which for him was related to a lack of stress from social judgements. "No, he came to Tunisia on holiday with us last year, that's the first time we've taken him abroad on a plane, and he loved every minute of it. Uh, we've never changed anything purposely for him, we've always said that people can take us warts and all, we still go into restaurants and the like, his favourite place is Burger King and we take him in there and there have been times that Jesse decides that he wants to take his shirt off and his trousers off 'cos that's one of the things that he does, and he's done it before and all right you get a few people looking a bit oddly at him but . . . fine!" (Paul: 10.19).

Social Support:
A response common to all the participants was that of calling on support from others, mainly family. Fathers valued support from their families and other people around them, both practical and emotional. However for some fathers there was a tension between wanting support and wanting independence. "But you've got to be able to
open your mouth and ask for this help or go out and find it. That can be, daunting is too strong a word, but it can be difficult. It doesn’t come naturally, you don’t just go up to people and tug and say I need help with this, do you?” (Mark: 13.12). He described how he and his wife were both “quite independent” (Mark: 16.3) and held this to be an important causal factor in them not having lots of support from their own parents, “having spent much of our formative years refusing help and wanting to stand on our own two feet, so they get into the habit of not helping you.” (Mark: 16.22).

Colin, when asked what kinds of support they had asked for replied, “We haven’t really asked for any. I don’t actually think... well, let’s be fair, we had two very good sets of grandparents and without those this problem would have been ex-fold more difficult.” (Colin: 22.8). This shows how much the family input had been valued, but how for Colin this support fitted with their expectations, unlike in Mark’s account.

Trust was an important part in participants’ decisions around informal support. The type of informal support uppermost in most fathers’ minds was, “...having someone look after him that you can trust” (Henry: 13.16), but it also appeared to be about feeling supported, as well as having practical help “in terms of support... we were very lucky with our family, I mean they, they just were there. They didn’t know what to do, but they were there” (Phil: 25.20).

Here the marked distinction between the rules for family and the rules for other people are illustrated, “Going to new people’s houses is a nightmare. But the only places that we really don’t feel any compunction about is the two sets of parents. That’s their problem. They’re grandparents and they’ve got to put up with their granddaughter, and if they can’t de-Chelsea their house properly then that’s tough luck, and what we do is let them follow her round when we go there!” (Colin: 14.27).

Fathers described how they drew on their parents, parents-in-law, siblings, and their own teenage children to care for their autistic child. Several fathers described how they found it difficult to trust other informal caregivers (baby-sitters etc.) “there aren’t
that many people you can trust to baby-sit” (Henry: 13.8) and this was interpreted as being part of the reason that only close family members were reported as being trusted enough to offer parents respite breaks, “Um, family wise, we probably use Helen’s mother more than we would have. We use her so we can go out and do things together.” (Henry: 13.6).

Mark linked this specifically to autism, in contrast to his feelings about his other children.

Andy: “Do find that kind of support to be more important and helpful because of Andrew’s autism, or would it be just the same if you had three kids without diagnoses?”

Mark: “Hmm, I wouldn’t like to over emphasise it, but yes it is. Because Andrew is not having a good day today, I know that if Kay my sister arrives and he’s not having a good day she’ll just say hello it’s aunty Kay and he’ll respond to that and it doesn’t matter that he’s crying and that. If it was just another baby-sitter arriving then I wouldn’t hand over Andrew in a non-co-operative mood to anyone else, it would have to be close family or very close friend. It’s a trust thing and also I would, it’s a British thing, I wouldn’t want to ask more than I’d be prepared to do.” (Mark: 14.21).

How professionals become trusted to look after an autistic child was not discussed. Mark’s anxiety around informal caregivers was related to the potential harm that his son might suffer due to being misunderstood, “if Andrew was really going into one then I’d hate to think that anyone would chastise him for something that he’s doing that he’s not doing anything naughty but because he’s not understanding. Both our sets of parents had different ideas, like smacking kids, now I’m not into smacking kids, and neither is my wife, whereas I’d hate to feel that Andrew might get a smack from somebody for being naughty when you know, he’d be crestfallen . . . he’s not doing anything wrong. I’d be really upset afterwards if someone had told him off and he’s just having a day when he can’t communicate, and it’s that they haven’t got the skill to actually talk to him. That’s my problem with leaving him with somebody else.” (Mark: 15.13). This links to the previous section in which fathers’ perceptions
of their child’s increased vulnerability due to their autism, and hence the fathers’ increased feelings of responsibility to protect them, were salient challenges.

Services:
Participants also defined responses which were set within their understanding of, and interactions with, services. The need to be proactive parents emerged from many of the fathers’ accounts. Most held that this proactive stance had to be shared by both parents. “My wife literally shook everyone until she got what she wanted, ‘cos they were very, they didn’t want to statement him, go down that path just yet, he was too young. And literally just getting him on that road, ‘cos initially they just said that he had learning difficulties, the hospital, and we said no, we don’t think he has there’s something more intricate going on and we had to fight tooth and nail for them to even label him as on the autistic spectrum.” (Paul: 15.27).

Along similar lines, Colin described his response being like a ‘business’ approach to interaction with services, basing it on advice he had received at a talk in the early stages after his child’s diagnosis, “try not to battle with them too much, the resource has to be shared amongst a lot of people, don’t expect the earth all the time, just try and get what you can out of the authorities, ‘cos if you get their back up you’re gonna get nothing. Good advice.” (Colin: 27.10). This challenge arising from services and the need to be proactive in order to get the best outcome for their autistic child was noted by the majority of participants. Ivan was an exception who had not until the time of the interview been directly involved with services as he had been working abroad. Henry suggested that these service challenges might be a factor in the high level of father involvement with autistic children (a response) which he had seen locally, “I guess you also, interestingly see more involvement by the fathers, you know usually it’s the mums who pick the kids up from school, but I guess you do feel that you have to give more support to the wife, to your wife, so yeah, you do see more of the guys there than you’d think.” (Henry: 18.21).

The responses of some fathers to the challenges arising from services contained the belief that two heads were better than one. Being the second head therefore became an important part of a father’s role. Mark summarises some of these points from the
professional’s point of view, “And it’s only human nature, you know if you only get one parent and they look like they’ve got somewhere better to be then they aren’t going to try as hard are they? So as a father I think you have to be visible, and supportive at the meetings, that’s just the decoration, but then to listen to what you get from the meetings and try to come away and put it into practice at home.” (Mark: 23.21).

The need to be proactive with services, feelings of responsibility and awareness of the weightiness of the system, were related to fathers’ wish to be involved in a collaborative process over their children’s care. “We had a really good speech and language therapist, and psychologist. They were brilliant in that we could have that discussion, of well I’ve tried this, and even though they thought that might be wrong they didn’t say oh you shouldn’t have done that, they gave me different ways to do things, try things, and just those discussions, being able to bounce ideas around, and they would throw things at us, and we’d say well we’d tried that, and that didn’t work, that was, it’s been a big part of coping. And contact with the school, I go to the school regularly, even when I was in full-time employment I went to the school regularly, setting targets for him. So, that involvement, so that the medical and the educational people haven’t taken charge, we’re in there as a little gang all together . . . that’s been very helpful.” (Phil: 17.26)

The wish for collaboration was keenly felt as far as medical professionals were concerned,

Mark: “Um. This dietary thing, we’ve been lucky to have doctors at the hospital and a G.P. take an open mind as to whether it’s useful or not, ‘cos medical opinion at the moment is very much undecided . . . Now, because they were quite tolerant about the notes we kept about all this then we hope that the doctors will be just as supportive over the dairy as the gluten free diet.”

Andy: “So the fact that the doctors kept an open mind about this . . . ”

Mark: “Despite saying at first well there isn’t a lot of evidence for it, if you want to do then do it, and we’ll monitor it for you, and as long as we kept reasonable notes they’ve been reasonably supportive.” (Mark: 16.31).
In summary, then responses included changes to personal attitudes, family roles, work patterns and perspective on it, social life, and family activities. Responses also included the use of family support, specialist services and personal research. A proactive, shared (see below) and problem focused approach was seen as important both in relation to services and for the health of the marital relationship. Participants did not note the use of wish fulfilling or religion.

3: Unexpected findings.

Benefits to the Marital Relationship:

Moving away from fathers' responses, there were an unexpected finding which demonstrated not a challenge, nor really a response. This theme came about from a neutrally worded question about how participants' marriages had been effected. Several fathers discussed how having an autistic child had produced benefits in their marital relationships. Colin held that, "it makes it stronger. It will do one of two things, it'll drive you apart or it'll make you stronger." (Colin: 20.8). This finding was a surprise but emerged from the majority of accounts and was clearly important for fathers to explore. Phil held that family cohesion "a bonded family around them" (Phil: 34.10) was especially important in families with an autistic child.

Fathers also discussed how these benefits came about. Several fathers view was that the important thing was having a joint approach and being able to talk about the difficulties openly, "it's something that we both have in common that we really both sit down and talk about and try to deal with. So, I would say no, if anything it's made ours stronger." (Colin: 21.9); "... I suppose we are stronger 'cos we both try to pull in the same direction and I think if we were pulling differently then there might be problems, but we seem to have agreed that this is the way we'll handle it this is the way we're gonna do it and ... I suppose there's no set rules about what to do but we are in agreement and everything seems to be fine at the point. I think we seem to be, we converse a lot about him, if there is a problem with him then we'll have a chat about it rather than one of us try to deal with it, talk about it and deal with it together." (Paul: 13.25).
Lack of Male Staff:
Several of the fathers commented spontaneously on the lack of male staff across the medical and educational services for their children in this area, "in fact it's a rarity talking to you, 'cos you're probably the first male I've spoken to about this problem" (Colin: 25.23). No question had been asked about gender of professionals. Henry described that there was something unique or different about the quality of male interactions and that children are missing out on this input in current services, "I guess fathers also have a different view 'cos all or most of the kids are boys and all the teachers are girls, bar one. O.K. it's happening all through primary levels, there aren't enough male teachers, but in a case like this where you're dealing with autism which the majority of them are boys . . . um . . . I don't know, is there something that they're not getting, that they need from a male role model even for autistic children. I just know like I was there this morning and it was like . . . . no blokes." (Henry: 15.26).

Fathers discussed the effects of their own gender in relation to services. Henry and Mark talked about how they were treated differently by professionals than mothers. Colin and Ivan felt that overall there was not a difference in the way they were treated due to their gender, except that "The only maybe thing is that they are a little bit more sympathetic to the women. But that's because of the nature of life I say, they are more likely to be upset about this type of thing, I presume some men are, but would have said very few, so not treated differently really in any other way." (Colin: 25.19).

Only Henry described his gender as a challenge in relations to professional interactions. He felt that his gender presence as a tall and robust man would effect the interactions with the mostly female professional staff who he had encountered, leading him to respond by withdrawing from these interactions a little, "it's a different kind of interaction . . . they are not going to react in the same way, . . . say there's a problem, you tend to leave that to Helen, 'cos you think I might get on my high horse and people wouldn't take it too well." (Henry: 18.11).
Discussion

This section discusses the study’s findings and compares them to those from the previous research discussed in the Introduction section.

*Breadth of Definitions:*

The findings suggest that fathers define the challenges arising from their children’s autistic disorders as deriving from the child’s vulnerability, the effects on their family and partner, from within themselves and from outside the family. Responses ranged from changes to personal attitudes, researching, changes to work patterns, family role changes and use of social support and services. The wide range of identified challenges confirms the importance of variables from all four classes described in the introduction (child, parental, family and contextual). Consequently the findings support the use of multidimensional models of coping and stress such as that proposed by Crnic et al. (1983).

*Contextual Variables, Time and Work Performance:*

Influences external to the family were present in fathers’ construction of the challenges facing them. These influences, as well as those from social judgements (below), included practical time-pressures from work and feelings of not performing well at work due to tiredness. This finding relates back to the importance of using multidimensional models, and highlights the importance of using measures of parenting stress which are designed to access contextual variables and are standardised on mixed gender and culturally appropriate parental samples. Current questionnaires such as the QRS and PSI are therefore less likely to be usefully applied to fathers, as they do not sensitively access these types of outside influences.

*Social Judgements:*

Challenges were derived from fathers’ experience of negative social judgements about their children and themselves based on their children’s unusual behaviour in public. Fathers’ responses varied from limitations on family activities (possibly relating to previous findings of ‘social withdrawal’; Gray, 1994) to conscious decisions to maintain these activities and defending their position with use of the autism label.
There was evidence that some fathers underwent change in their attitude toward social judgements because of their experiences. Fathers who reported being less effected by social judgements, due to their character or through personal growth in this area, were those that reported maintaining more normal family activities. Frey, Greenberg and Fewell (1989) found that the important component of fathers’ social support networks was a lack of criticism (unlike the case in mothers). Together these findings suggest that an important component of fathers’ parenting stress centres on negative social judgements and that attempts to help them manage these difficult experiences is warranted at even a pre-diagnosis stage. Ratings of spouse’s coping efficacy have been found to be related to parental stress in both genders (Frey et al., 1989). Therefore helping fathers with this issue, possibly through brief CBT interventions, may also impact positively on their partners’ experience of stress.

Challenges from Behaviour:
Challenges from child behaviour and specific behavioural management responses were common to all of the participants. However, as described in the introduction, frequencies and topographies of specific behavioural challenges were not the focus of the study and so are not dealt with in detail here. On an interpretative level however, fathers constructed behaviourally based challenges deriving from difficulties in establishing discipline in children with ASDs, difficulties in communication and the vulnerability deriving from a lack of safety behaviour or social understanding.

Vulnerability Attributions and Heightened Responsibility:
Vulnerability attributed to the child as a result of their ASD emerged as a theme from fathers’ accounts, and was often related to lack of safety and social behaviour on the part of the child. This seemed to underlie the reported heightened feelings of responsibility toward the child with an ASD. Future studies might usefully examine the components of fathers’ constructions of vulnerability and responsibility. Both child characteristics and fathers’ beliefs about the protective role of parents would be likely to impact on this issue.
**Communication:**
Fathers reported having to devote time and effort into learning to communicate with their children with ASD and to understanding what they were trying to communicate on a daily basis. Previous studies have likewise found communication problems to be rated as highly stressful in parents of children with autism (Bebko et al., 1987; Gray, 1994). The current findings illustrate how communication difficulties may mediate parental stress through the time demands that they impose.

**Constructions of Autism:**
In the current study, the label of autism was seen as being a double edged sword. Having a diagnosis and hence a label of autism was seen as removing some of the challenge derived from uncertainty. The label was also seen as facilitating fathers’ problem focused approach. But the label also meant admitting their child had additional needs, having other people labelling their child and leaving them open to negative social judgement and the difficult emotions of loss and heightened responsibility. The label was also seen as enabling them to access appropriate services and meet their child’s needs. These findings confirm and extend similar findings from Midence and O’Neill (1999).

The current findings showed that within this group of fathers, all knew a substantial amount about the autistic spectrum and were aware of the wide range of presentations that children with ASDs can show. This relates to the findings of Tams (2001) where ‘heterogeneity’ emerged as a theme in parents’ (mostly mothers’) accounts. The current study extends our understanding of this issue as it clarifies how this appreciation of the autistic spectrum came about for fathers. It was found to be based on fathers’ personal observations of other children (through nursery, clinic and school visits) and through the common coping strategy of research (see below).

Frey et al. (1989) found that the ‘comparative appraisal’ component of parental coping was particularly important for positive outcome on parental stress and distress. This construct is one which centres on the comparisons parents habitually make in order to judge their own situation and that of their child. In the current study, fathers’ frames of reference for comparisons was both to non-autistic siblings and to their self-
constructed picture of the heterogeneous autistic spectrum. Providing fathers with accurate information about the heterogeneity of autism will thus impact in either a positive or negative direction on their stress and distress via ‘comparative appraisal’. Consideration of parents’ appraisals and developing frame of reference throughout the child’s assessment is therefore likely to be a useful tool for professionals to use in families indicating high stress or distress.

The current findings indicate that the life-long implications of the diagnosis of autism are salient and challenging aspects for fathers of children under 6 years of age. This finding confirms and extends the previous quantitative finding that ‘life span care’ was an important factor in parental stress that discriminated parents (no gender data) of children with disabilities and normal development (Salisbury, 1984). In the current study a link is made between the importance of life-long care needs and fathers’ role definitions and sense of heightened responsibility to provide for the child’s longer term needs.

Some fathers in the present study reported using the label of autism as an explanation to other people, to avoid negative social judgements. This response relates to the particular challenge of the physically hidden nature of autism. The current findings indicate that fathers’ perceived the normal appearance of their autistic child to be a component in their sensitivity to the challenge of negative social judgements. This relates to and confirms the finding from Midence and O’Neill (1999) where ‘invisibility’ was a theme in parents’ descriptions of autism.

Fathers’ Responses - Research:
Parents of children with Down syndrome or autism have previously been reported to use ‘information seeking’ as a coping strategy more than fathers of developmentally normal children (Rodrigue et al. 1992). Most of the fathers in the current study used this research strategy at some stage and this often took the form of accessing the Internet for diagnostic criteria and treatment options. This finding highlights the value of providing up-to-date, accurate and professionally acceptable information on the Internet by the National Health Service, Department of Education and other interested organisations.
Responses - Family Support, Service Use and Trust:
All of the fathers in the current study reported using autism services and where available, family support as major coping strategies. Support was defined as being primarily practical but also emotional when derived from family members. This confirms similar qualitative findings from the mixed gender samples of Gray (1994) and Midence & O'Neil (1999). Trust, relating to the vulnerability of the child and awareness of the level of behavioural challenge they might present, was an important variable in fathers' constructions of appropriate support. This underlay many of the fathers' reservations about using non-family babysitters.

Responses - Problem Focused Approach:
Fathers tended to adopt what they described as a problem solving approach to the challenges they were faced with. Previously, 'problem focused' coping has been found to be linked to better outcomes (on measures of stress and distress) in mothers and fathers of children with Down syndrome and cerebral palsy (Frey et al. 1989). The current study extends this finding by exploring what fathers consider problem focused coping to be. In this sample it involved approaching and analysing problems (e.g. behaviour, communication problems) without being drawn by difficult emotions or thoughts of wider concerns.

If the problem focused approach is a good reflection of fathers' thinking and behaviour during the process of assessment then they constitute a major resource for the family, child and service. Professionals might usefully seek ways to facilitate their engagement in the assessment process and mentor this problem focused approach throughout their interventions with families.

Responses - Social Networks:
Social networks have been previously found to be reduced in fathers with children with developmental difficulties (Trute and Hauch, 1988). Fathers have also previously been found to make more substantial changes to their social and leisure activity as a result of having a child with ASD than mothers do (Rodrigue, Morgan and Geffken, 1992).
Although the present findings do not address this issue of differential change, most of the participants reported reductions in, or limitations to, their social activities.

Fathers did not report significant support being gained through social aspects of work relationships. Most fathers kept work and family-life quite separate and did not confide about their child’s difficulties to work colleagues. This was an unexpected finding and it runs against the traditional view that fathers have access to support networks through work which non-working mothers do not.

Fathers’ mostly defined their networks as being family members and a small number of close friends. Changes and reductions in social life were commonly described as reductions in the couple’s social activity, indicating that fathers did not define their own social needs as being largely separate to that of their wives. As informal support networks have been found to mediate parental stress (Copeland, 2000) fathers in the circumstances described in the current study may be less supported than assumed by professionals and hence more vulnerable to stress.

Responses - Changes to Work:
The current study indicates that fathers of children with ASDs reported significant changes to their career outlook and their work practice. Several fathers had changed jobs or turned down promotions in order to be best able to support their wife and child due to the additional needs of their ASD. The large scale of such changes was not expected prior to the study as it has not been previously reported. This was probably due to sampling bias toward mothers and the lack of widely-defined coping response inventories in previous studies. This is an important finding because of the life-long personal impact on fathers and their families of having to make such changes. It is also important because the fathers in this sample were all the major earners in the households at that time, and the care needs of the child with ASD meant that one parent was unlikely to be able to return to work until the child was in full-time stable education.

The perceived necessity of these changes (change of job, reduced working hours, increased flexibility) would make such issues extremely challenging to fathers in less
stable financial positions or those whose employers were unaware of their difficulties or unsupportive. As fathers reported keeping work and home separate there is also the issue of whether fathers will wish to inform their employer of difficulties.

Responses - Roles and the Couple:
Fathers in this sample talked about joint (couple) role definitions, and the overall finding was the level of flexibility which characterised fathers’ (the couples’) thinking about roles. Fathers reported being involved in their children’s day to day care, usually daily after work, at weekends and for service interactions. They described how their roles had changed dependent on a variety of characterological, practical and cultural factors.

There is some evidence from the study that fathers saw their roles as being more centred on longer-term considerations than their partners’, such as the financial arrangements for the child’s adulthood. This finding may relate to the previous finding that fathers’ reported stress continued at a high level as the child age increased despite reporting a reduction in child symptom severity (Bebko et al., 1987).

There were many examples where questions about personal responses were responded to with answers about the couple’s responses. This indicates that in some ways the split between fathers’ and mothers’ coping and experience of stress is an artificial one. In a sense, in two parent co-resident families, parenting stress in fathers and parenting stress in mothers do not form comprehensive enough constructs. Only by looking at both an individual level and at the level of the couple as a unit, can research access all the factors involved in coping, such as the role adjustments indicated in this study.

Unexpected Benefits:
The current study produced the unexpected finding that several fathers reported benefits arising from the challenges presented by having a child with an ASD. Fathers constructed these benefits as arising from the parental couple’s response to their children’s needs. The response which lay beneath these benefits was talking in depth about their child and developing a joint and shared understanding and response to
those needs. Marital strain on the other hand, was explicitly linked by one participant to a difference in coping strategy (one person problem focused, the other avoidant).

**Responses - ‘Wish fulfilling’ and ‘Religion’:**
In the present study there was no evidence of ‘wish fulfilling’ as a coping strategy. This negative coping strategy on the WCS (see Introduction) has been linked to poor outcomes in parents of children with disabilities (Frey et al. 1989). This might reflect the participants’ use of research, problem focused coping and their realistic understanding of their children’s needs and prognosis compared to that of previously studied samples. There was also no evidence of ‘religion’ as a coping strategy (previously found by Gray, 1994), and again cultural / contextual factors may have played a large part in its absence.

**Relation to Services:**
Participants spontaneously noted a lack of male staff in services and some felt that this meant that their children were missing out in some way which was not clearly defined. As there is a high male to female ratio in the prevalence of ASDs (Introduction) it could be argued that recruiting more male teachers, Speech and Language Therapists and other health professionals would be especially important for the well-being of children with ASDs.

Fathers had mixed opinions on whether gender effected professional interactions, though most noted the importance of fathers’ involvement in the assessment and diagnosis process. Fathers gave clear descriptions of what they valued and didn’t value in services. There was a valuing of a collaborative approach between health professionals, schools and parents. At least partial experience of this was reported by the majority of the participants. Fathers also expressed a wish to have more clear recommendations about school placements from health professionals. Several fathers described that health professionals would only suggest the range of options without giving opinions on which would be the most appropriate. Fathers however, reported a wish to have some clear guidance specifically on this issue. This is especially important as fathers described concerns about educational placements as being one of the major challenges in having a child with an ASD. This was related to the fathers’ construction
of the importance of making the right decision, their responsibility to make the best option available for their child and their understanding of the lifelong implications of appropriate / inappropriate education in children with ASDs.

Importantly, the majority of fathers noted challenges deriving from the educational statementing process (paperwork and negotiations) and the educational placement of their children. This is similar to the ‘battling for services’ described by Tams (2001) in a sample of mainly mothers of children with autism. In the current study, the concerns were more specific, probably as a result of the age of the children and the current importance in fathers’ minds of the child’s first placement. Stress deriving from such concerns should therefore be considered carefully in any assessment of parental stress in fathers.

These related issues, based as they are in a U.K. service provision context, need to be addressed by professionals in the U.K. at a local level. The importance of initiatives to support parents with the statementing and placement process (such as the use of Parent Partnership Officers) are highlighted. Initiatives to support parents with making long-term financial arrangements could be addressed through national voluntary agencies.

The current participants’ accounts are consistent with Howlin and Moore’s (1997) findings that the assessment process for children with ASDs can be a difficult one. The present study helps to clarify what it is about this process which is stressful and what impacts upon fathers’ experiences of this. Critical variables in this process were fathers’ developing knowledge of ASDs, the impact of the life-long aspects of the diagnosis, and the pace at which these developed alongside the assessment process. Fathers’ experiences of either shock or relief and confirmation, were interpreted as hinging on these variables (see also ‘comparative appraisals’, above).

Howlin and Ashagarian (1999) report that the average age of diagnosis of children with ASD in the U.K. was 5.49 years. In this sample all children had received diagnoses before the age of 5. This possibly indicates the success of the local service models and the availability of local expertise in this area. While participants regarded services as being under-resourced and geographically patchy, they also found the pre-
school autism services to be inclusive and reported high levels of satisfaction with their children's progress while attending the Autism Assessment Nursery.

Considerations on Method:
From the perspective of the interviewer, the interviews themselves had a relaxed and personal feel. Most participants reported that the interview had been an interesting and pleasant experience. Some said that exploring their experiences with someone else had produced new or different perspectives on them. From my perspective at the end of the research process, it felt as though the participants had allowed me to join them in their spontaneous exploration of their own experiences and that my questions merely acted as catalysts for this process.

The interview schedule (Appendix 1) was effective as a tool for eliciting experiences, thinking and emotions, as attested to by the large amount of data produced. The semi-structured format allowed the interviewer to follow the particular experiences and themes presented, in appropriate depth for individual participants, whilst covering the researcher's a priori areas of interest. Following individuals' particular concerns may have been largely responsible for the rapport and openness which developed in the majority of the interviews. The emergence of unexpected findings (see above) also attests to the appropriateness of this form of interviewing in studies which aim to explore experiences rather than measure them.

Limitations of the Study:
As discussed in the Introduction and Method this study did not aim to be widely generalisable. The data and analysis serve to illuminate the experience of challenge and response of a particular group of fathers in a fairly tightly defined context. All the fathers were cohabiting with their wives in a family home with the child with an ASD and most often along with non-autistic siblings. The experiences of non-resident fathers would be likely to be very different to those found here. Those of single parent families and those with less amenable living arrangements might also be expected to be different to those found here. All the children in the study were under 6 years of age and the majority of fathers reported positive experiences of the specialist autism services available. As challenges derived from the educational system were salient,
fathers of older children who have been in the educational system for longer would be likely to differ from those in this sample.

*Research and Practice:*

Future quantitative research could aim to develop comprehensive parental stress measures appropriate for use with fathers in the current U.K. service provision and cultural context. To this end, research could access a regional or national sample of fathers and aim to compare responses on a multidimensional assessment based upon the challenges and responses identified in this and previous qualitative and quantitative studies. Initially, using multiple existing standardised measures of parenting stress, coping, appraisals etc., (as in Frey et al. 1989) would be appropriate if carefully chosen to cover the range of challenges and responses identified in this and previous studies. The use of relative ratings of perceived challenge is warranted, to reflect the heterogeneity displayed even in the current study’s seemingly homogenous sample. Sampling fathers of children of different ages, socio-economic backgrounds, educational stages and from different family constructions (including single fathers) would be illuminating.

The current findings suggest that clinicians should use multidimensional models of stress and coping when assessing fathers of children with ASDs. The importance of challenges situated outside of the family (contextual variables such as work, time, educational system and social judgements) are highlighted in fathers’ experiences. The breadth of responses found also highlights how fathers’ coping can involve personal, role, couple and external changes of considerable significance. An awareness of the breadth of possible stress sources, the variety of coping responses and the role of individual constructions and attributions in these, can further inform clinicians in their assessment and work alongside the families of children with Autistic Spectrum Disorders.
References


phenomenological analysis. In M. Murray and K. Chamberlain (eds). *Qualitative


Tams, R. (2001). Parents' Perceptions of Autism, a Qualitative Study, in J. Richer and
S. Coates (eds). *Autism, the Search for Coherence.* London: Jessica Kingsley

Adaptation to the Birth of a Developmentally Disabled Child. *Canadian Journal of
Community Mental Health,* 7, 5-16.

Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J. A. and Walsh, S.
(1997). Standards for Research Projects and Theses Involving Qualitative Methods:


Open University Press.

Wing, L. and Gould, J. (1979). Severe Impairments of Social Interaction and
Associated Abnormalities in Children: Epidemiology and Classification. *Journal of
Autism and Developmental Disorders,* 9, 11-30.

Interview Schedule

Introduction:
This interview schedule is the basis for a semi-structured interview. Once the initial question on each theme has been asked, questioning will follow the material brought by the participant. For each theme, a range of possible questions are given.

Interview Questions:

1: Caring for a child with an autistic disorder.

What challenges has being the father of a child with an autistic disorder confronted you with?

In what way do you think these challenges are similar or different to those faced by parents of children without similar diagnoses?
(or How have these challenges been the same or different to those from caring for your other children?)

How have you made sense of the challenges which caring for your son / daughter has raised?

2: Personal identity as a father.

In what ways do you think being a father of an autistic child has affected you as an individual on a personal / work / social level?

Do you consider that other adults think of you differently because your child has a developmental disorder? How do you make sense of that?

How do you consider the role / challenges / position of a father of an autistic child to be different from other family members?

3: Coping and support.

How have you coped with the varied challenges of parenting a child with an autistic disorder?

What kinds of support have you asked for during the first few years of caring for your child?

How do you think the needs of and / or the pressures on, fathers differs from those of mothers, if at all?

In what ways do you feel you could have been more / better supported?
4: Relationship to services and the process of assessment / diagnosis.

How would you summarise your experience of the process of assessment and diagnosis of your child?

How do you think your experiences of this process as a father, differ from those of mothers going through the same process?

How would you describe your experience of on-going statutory services (including and local health and social services)?

If a male friend suspected that their young child might have autistic traits, what advice would you give him based upon your particular experiences?

5: Ideas for the future.

In what ways do you think could better address the needs and wishes of the fathers of children attending the centre?
Participants’ Introduction Sheet

Study Title:
Exploring the Experiences of Fathers of Young Children with Autistic Disorders: A Qualitative Study.

Invitation:
You are being invited to take part in a research study. Before you decide whether to take part it is important that you understand why the study is being done and what it will involve. Please read the following. Please ask if there is anything you are unsure of.

Purpose of the Study:
Psychological research into stress and coping in parents of children with an autistic disorder has tended to focus on mothers’ views or not discriminate between mothers’ and fathers’ views. Previous research has often used questionnaires that can limit participants’ responses or are based on other peoples’ definitions of stress and coping. This study takes a less constrained view, by asking you to describe your experiences of being a father of a child with an autistic disorder. We are interested in what you have found stressful in caring for your child, and about any stresses in the process of diagnosis and your ways of coping with these. We are also interested in how other people have acted toward you, be that positively or negatively and how you have felt about your child’s involvement in the service.

Who is Being Asked to Take Part?:
All fathers of children who have recently attended, or now attend the Autism Assessment nursery. Your contribution is very important as numbers are small and we have two months to complete the study.

What Participation would Involve:
Participation would involve you talking to the investigator (Andy) about your experiences of being a father of a child with an autistic disorder. The interview will take one hour and can be at a place and time convenient for you. Andy will guide the direction of the interview to cover the aims of the study, but you will be free to answer in your own way and the interview will be conversational in style.

Confidentiality:
Your interview will be audio-taped. The interviewer will then make a transcription and all names and other identifiers will be removed. The tape will then be destroyed.

Who is Running the Study?:
The study is being undertaken by , a final year Trainee Clinical Psychologist from the University of Surrey. Andy will be conducting the interviews (Chartered Clinical Psychologist at the Nursery) will also be available for you to talk to if you have any queries or concerns.
Your Right to End your Participation:
You have the right to end your participation in the study at any time. The interviewer (Andy) and the psychologist overseeing the project (Dr. ) would be available to speak to you afterwards should you wish to, but there is no requirement for you to explain your decision to withdraw.

What Will Happen to the Information I give?:
The anonymous transcriptions will be used as the basis of a doctoral thesis at the . This can be accessed via the University Library after Sept 2002. Anonymous views and findings will be discussed with the team. The study may be submitted for publication in a psychological journal at a later date.

Ethical Approval:
committee, which has both qualified and lay members has scrutinised the procedure and details of the study. Their approval has been attained.

Thankyou!
Thank you for taking time to read this information. If you have any questions at all feel free to ask.

Contacts:
[Researcher]

[Supervisor]

[The University]
Consent Form

As part of a research project, I would like to invite you to share with me some of your experiences and feelings around having a child with an autistic disorder. Some of the issues that are of particular interest are: fathers' definitions of the stresses in having an autistic child, how fathers have coped with these stresses and whether fathers have felt included in their child's healthcare services.

To do this, I would like to complete an interview of approximately one-hour in length with you. Care will be taken to ensure that you (or any person that you mention) can not be identified through the research report. The interview will be audio-taped, and in making a transcription of the audio-tape, any names will be deleted or replaced by pseudonyms. After the transcription has been made, the audio-tape will be physically destroyed.

If there are any questions which you do not wish to answer during the interview, feel free to say so.

If there are any questions you would like to ask during the interview, please feel free to do so.

You are free to withdraw from the study at any point without needing to justify your decision.

Please read the following statement.
If you are in agreement, sign where indicated.

I confirm that I have read and understood the above information. I agree that the purposes of this research and what my participation in it would entail, have been explained to me in a manner that I understand. I therefore consent to be interviewed about my experiences and feelings about having a child with an autistic disorder and the issues of stress and coping in this context. I also consent to an audio-tape of this interview being made and to the recording being transcribed for the purposes of this research.

Signed: ............................................ Date: ........................................

Please Print Name: .................................................................
I undertake that confidentiality will be ensured in respect of the participant’s audio-taped interview and transcription of the same. I also undertake that any use of the audio-tape or transcribed material will be for the purposes of research only.

The confidentiality of the above participant will be protected and they will not be identifiable to others who are not already familiar with the circumstances described, through the research report.

Signed: ........................................ Date: ....................................

Please Print Name: .................. ..........................
Appendix 4: Copy of Local Research Ethics Committee Approval Letter.
03 October 2001

Dear Mr Gentil

Fathers of pre-school children with Autistic Disorder who have attended the Springboard Autism Assessment Nursery: Developing a local model of stressors, personal coping and perceived needs (ACE/2001/68/Psych) – FAST TRACK

I am writing to inform you that the University Advisory Committee on Ethics has considered the above protocol (and the subsequent information supplied) under its ‘Fast Track’ procedure and has approved it on the understanding that the Ethical Guidelines for Teaching and Research are observed. For your information, and future reference, these Guidelines can be downloaded from the Committee’s website at http://www.surrey.ac.uk/Surrey/ACE/.

This letter of approval relates only to the study specified in your research protocol (ACE/2001/68/Psych) - Fast Track The Committee should be notified of any changes to the proposal, any adverse reactions and if the study is terminated earlier than expected, with reasons.

Date of approval by the Advisory Committee on Ethics: 03 October 2001
Date of expiry of approval by the Advisory Committee on Ethics: 02 October 2006

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Advisory Committee on Ethics

cc: Chairman, ACE
    Dr M Finlay, Supervisor, Dept of Psychology
    Dr M Tostevin, Field Supervisor, Springboard
A: (Intro and question about terminology) . . . are there any of those that you aren’t happy about me using, or any that you don’t think are appropriate?

S. Oh, I couldn’t really give you a comment on that one, it’s just um, we, mostly what we talk about is the autistic spectrum. I mean that’s what we’re told, that Chelsea is somewhere on the autistic spectrum.

A: Right.

S: So, as to all the others, I’ve not really come across them before. So . . . I don’t disagree with any of them.

A: So, you’ve been told that autism can be described as a spectrum and that Chelsea lies somewhere on that spectrum?

S: No. She’s on that spectrum somewhere, but no-one has ever told us where, on that spectrum she is.

A: Ah, right. So how do you think you’ve come to understand what this ‘spectrum’ means?

S. Um, well, we know what the spectrum is ‘cos we’ve been to [School] and we’ve been to [School] to look at the different types of children that are on the spectrum, so we can see how wide the spectrum can actually be, and also from the fact that I’ve got a daughter that’s one.

A: So, you’ve defined it for yourselves by looking at children that you’ve seen . . .
MRP Appendix 5: Example Transcript - Colin

S: Exactly right, looking at children that we've seen, my brother in law's little 'un is no where near as severe as what Chelsea is, so I can see a mild end to it, but also, even how it effects children at the mild end. So, we don't know where she stands in the middle of all of it, but we've got our own views from just looking at other children.

A: O.K. Great. Now, I think we'll start to go through the questions here. The first question is what challenges has being the father of a child with an autistic disorder confronted you with? What do you define any challenges as?

S: Hmmm. One of the biggest challenges is, is, really not something to do with autism, it's the fact that I've got two children, and trying to explain to a very young child that there's a different set of rules for her than there is for her sister who has got the autistic problem.

A: So Chelsea and her sister are how old now?

S. Chelsea is 4½ coming up for 5 and F is 6½. So there's a year and a half between the pair of them. Now that has been a very difficult one to deal with.

A: So finding a way of explaining to someone who's 6 that .

S: That what her sister does, it's not acceptable for her to do. And that's been a real difficult one to get over.

A: So implied in that, there's different rules for the two of them, different reactions . . .
S: Yeah, the meal table if Chelsea wants to get up and walk about, we can’t really say to her no you can’t, ‘cos we wouldn’t eat our own dinner, but for Holly, we don’t want her to get up and walk around during the meal time.

A: Mmmm. Has that been most difficult for her, or for you?

S: I think it’s been difficult for both, ‘cos you’ve got to make the rules as well, and you do feel like a bit of an ogre at times. Um, letting one child get away with it and the other one not. As to other problems we’ve had, it’s . . . you never know what they are going to be. And what is the problem for this month won’t be the problem for next month, and it won’t be the problem for the month after.

A: Ah, for instance?

S: Like, this month C’s sleeping. She’s . . . gets up in the middle of the night and joins us in our bed, alright, fine if she goes back to sleep, sometimes she doesn’t, sometimes she’s up all night. Um, the month before that we tries to address toilet training. Now, what that brought about was C’s awareness that she was wet, so all she did was take all her clothes off. And did this repeatedly, all day long. Now that came a real big problem, and like, the new problem is that at school they like to get them used to textures, pouring things out . . . well at home now, if we don’t lock everything up, Sunday the entire contents of washing powder on the floor! There’s all these different problems, like, and it’s, it’s something like you have to address with the school as well, things like this . . . clinical psychology has been very useful I must admit. But a lot of it is . . . um . . . common sense. For the
stripping problem we bought clothes and tied them on her. So
she couldn’t undress.

A: How long did it take her to settle from that?

S: Six weeks, six weeks.

A: So is that roughly the length that a single problem will
last, or is it quicker than that?

S: I would say it’s about six weekly that the problems come
and go. And they repeat each other. So you know the cures for
them, from the time before, but when a new one comes up . . 
you’ve got to really go through everything to work out what
you’ve got to do.

A: Yeah, are there any similarities to how F is in that respect?

S: I wouldn’t have said so no. No, F is definitely not like
that. Having an autistic child, you certainly notice autistic traits in
the other one regardless of whether they have autism . . . F flaps
an awful lot. And that is an autistic trait, I think so, and um, there
are lots of things she does that you think hmmm. But I’m
quite confident of F, that F is . . . is, it’s not nice to use the term
‘normal’ child, but you have to use it now and again, and she is of
that ilk, and quite bright as well. But we have the impression that
Chelsea is quite bright, from what she can do. But . . . who
knows.

A: In a different kind of a way?

S: In a different kind of a way. She’s a much more
mechanical person. She can watch you how to open a door, and
F wouldn’t have a blind idea how to open it. Chelsea will have it open in seconds.

A: An observer?

S: Much so. The school have said that there’s a bolt at the top, Chelsea will not try to door, she will look up at the bolt, see if the bolt is bolted, if it’s bolted she will not open the door . . . if it’s unbolted . . . through she goes.

A: Impressive. Are there any other challenges specific to being a father of an autistic child? Maybe specific to the autism bit?

S: I think, I don’t know if you’d regard this as a challenge or not, but . . .

A: (Open gesture)

S: When we found out that Chelsea was on the autistic spectrum, we went to an autism meeting, but we never repeated the experience again, but the speaker there was a psychologist, and she gave us one of the best bits of advice that you could ever give, ‘cos there were lots of people there saying, ‘my child needs speech therapy!’, and she said how ‘now is a speech therapy’, and the truth is . . . they need it twenty-four hours a day, and the only persons that are going to give them that is us, as the parents. And the challenge to us is to learn how to teach them, ‘cos you cannot do it as you would in a normal way, which is just talking. You have to . . . the first thing they told us was is we talk too much. That’s what we were told by the Speech Therapist, that everything is “drink”, “want orange”, don’t put words in that they don’t need to know. Everything has to be as simple as possible.
A: Yes that must be quite a challenge. Do you find yourself constantly monitoring what your doing then?

S: The problem you do is, that you do it with other people! And the other thing as well is that you’re supposed to do it from the other way round, so if Chelsea wants a drink you say “I want a drink”, not “do you want a drink?”. So it’s . . . yeah.

A: And that’s very different to what you’ve been doing with F at the same table, in virtually the same interaction?

S: Yeah, yup, exactly. So it’s very very difficult and of course we’ve got through P.E.C.S (Picture Exchange Communication System) as well, which is um, which is um . . .

A: How did you find that?

S: What PECS?

A: Yup.

S: Very very useful. It’s given us a line of communication to Chelsea. Rather than just her standing . . . blindly at the video rack, going “Uhh!” . . . you give her a picture of all her videos, ‘cos I took them off the web and made little icons, give ‘em to her and she gives you the one she wants to watch . . .

A: Brilliant.

S: Um, I’m not sure that LOVAAS isn’t a better solution, whereas they reiterate the words a great deal more, more than the PECS themselves. We’ve been told that PECS does not slow
down the language but . . . I'm not overly sure that it does. But .

A: Well, it's good that you're asking the question.

S: Yeah. But we do have a line of communication to Chelsea now.

A: Yeah. Can you image what it would have been like if she didn't take to that system?

S: We would have been trying every other system we could find. I tried sign language for a while, and that was . . . just totally disregarded. In fact the only one that got interested in that was F!

A: Oh!

S: But F is interested in languages, she's taking French at the minute at age 6. And she loved it as well, 'cos I took videos of the sign language to test it all out, but Chelsea didn't take to that at all. And . . . if this hadn't have worked I think we would've really had to've looked at LOVAAS. Although, I mean it, I think we'd have struggled. Purely because [Autism Nursery] now exists, so [County] has now fulfilled their, their criteria . . . so they will not provide LOVAAS as an alternative. Which is why [Autism Nursery] was brought about . . .

A: O.K. You've talked about a fair few challenges there. Um, I wonder. How do you think that these challenges of having an autistic child would differ from having a child with a developmental delay, say delayed speech?
S: Um. I think that there is, something that most parents will use . . . and it's not probably the best way of dealing with things, but it does get over it, it's called bribing. And you don't have that with an autistic child. And with, with, children that don't have autism, you can instill some sort of regime into them, such that they, five o'clock in the evening, they do expect to have their tea, at six o'clock in the evening they do expect to have a bath. Whereas that takes a lot longer with an autistic child. So I think that it comes from regime and every now and again the odd bribe that you have to throw in . . .

A: So there's an essential difference in the way that you can reinforce and place discipline on an autistic child, and that the key . . ?

S: Yeah I think really um I have less problems with it that what my wife does. I mean, my wife really struggles if Chelsea has a scene in side of a shop, she gets very embarrassed.

A: Right.

S. Whereas I'm . . .couldn't give a monkey's toss, I just pick her up and say . . . let's go for a walk. I don't have problems with it to tell the truth.

A: That's interesting. Um . . .how do you make sense of the challenges that Chelsea presents you with?

S: Ah . . . um I don't think you can (Pause). You . . . in a way . . . expect them now, you are just waiting for the next one to come round the corner. And . . . you do get some sort of stability like, for instance since she's been at [Autism Nursery] . . . there's,
there's a lot more cohesion between what they're being taught at
school and what they're being taught at home. So therefore, she
doesn't have two sets of rules to follow, you try and make it so
that she's only got one set of rules. But, making sense of what
she does sometimes... it... really doesn't make sense... why
take all your clothes off just because you've done something in
your nappy? Why not go and sit on the toilet? She knows what
the toilet is for. She will tell you, she will tell you “wee wee” and
she will point to the toilet, but why won't she do that, and how
do you get her to do that, and I have no way of telling you that I
can say I can make any sense of it what so ever.

A: Sure. Do you think about it, do you try to put yourself in
her position? Or do you try not to think about it?

S: I think I'm just too busy solving the problems. They're
there and they've got to be solved and some of them are
insolvable and you just have to hope that as she progresses that
the problem will eventually go away.

A: So you're more for the management and problem solving
side of things than trying to analyse it...

S: Yeah. I'm not that type of person. I'd love to know what
goes on in their little heads, and I'm sure that one day autism
won't exist, because someone will say this is what you do and
that will cure them. And I'm certain that that will happen,
because I think it's just such a small thing that's stopping them
doing what they want to do.

A: That's interesting. So you've a real hope that something
... that there is...
S: I don’t think it’ll be in my lifetime. I think it’s something that is very very small.

A: And that thing underlies everything else?

S: It’s a bit like everyone’s looking for a cancer cure and they’re making big strides to it, but no one is looking for a cure for autism, ...

A: ‘Cos it’s unthinkable?

S: Yep.

A: Okay, we’ll move on and think a bit about personal identity as a father. And the first question here is, How do you think being the father of an autistic child has effectuated you on a personal, work and social level?

S: Um.

A: You can take one at once or .......

S: Well, on a work level, I work in job which is very flexible and if I didn’t work there then I’m certain that my wife would not be able to work, having Chelsea. Because, the amount of things that you have to do to pick her up from places and to get her off to places and attend ... reviews, boards, all sorts of things, if X had to all of those then she would not be able to work, so I’m lucky from that perspective that I’ve got a job that if I want to go off at ten in the morning for an hour for an interview I can ... so from that point of view the only thing is that a few years ago I did look at changing my job and because Chelsea was Chelsea that
was stopped, we decided we could last on the money we’ve got 
and we’ll put up with whatever we’ve got to.

A: So autism from a work context has forced you to be very 
flexible and almost to pick a job which suits the rest of your life 
rather than fitting your life around your work?

S. That’s right. That’s exactly right.

A: Was that a conscious decision?

S: Yeah.

A: And, when did that start to be an issue, right from the 
word go when she was born or later?

S: No, well, she wasn’t diagnosed until she was nearly two 
years of age but there was always concerns and it . . at that point 
between the age of two and three was a time when we, a lot of 
time was needed to be spent trying to understand what we had to 
do as parents, to try to understand what we had to do to help her, 
what [County] was going to do to help her, it took an awful lot of 
time up, and it was apparent that that wasn’t going to abate 
probably for another five to six years, because each one of these 
stages is so small at the beginning of their . . .they’ve got nursery 
from 3 to 4, they’ve got the next stage 5, 6, and 7 and the next is 
8, 9, and 10 so all those stages are building up very quickly and 
you’re conscious that you’ve got to stay on top of that problem, 
because [School], [School] has 8 places a year, so if you’re gonna 
battle for those places you’ve got to be prepared to spend some 
time.
A: So it's quite an adjustment for you to make, and you say your wife is working?

S. Yes, my wife has started working now because Chelsea is attending [Autism Nursery] full-time so she started work in the Sept of last year so she's been at work for about 4 months now.

A: Ordinarily, if Chelsea hadn't had a diagnosis of autism would your wife have gone back to work much earlier?

S: No. No, I don't think she would have wanted to.

A: But it's affected your work pattern more than your wife's?

S: Yep. The only thing to say is that because they both would have been at the same school maybe X would have been able to do some work but because they are at different schools and they both have to be picked up at the same time, so that's why my job has to be flexible, or had to be flexible in the past. Cos now Chelsea goes on a bus and the bus doesn't arrive home until quarter to 4, and X can pick up F and be ready for the other one to come home. So it hasn't been an issue since Sept, but it was an issue before that.

A: That's an important change in your working lives. How about on a social level, how do you feel it's effected . . .

S. We have real problems with that . . . real problems. We have a large circle of friends who are very good but we feel much happier when we are at home. The house . . . is Chelsea proof. If she breaks anything then that's our fault. If we go to freinds houses . . . she had a period where she would write over every
wall that arrived, so we had to tell friends not to leave any pens
around, even if they’d have left one by mistake and she had
written on the wall, we would have been absolutely gutted, so
what we did was, when you went out was . . . following her
round for the entire time which is not what you’re going to see
friends for. Um . . . we have sets of friends who are very good
and they do de-Chelsea their house a little bit, and hopefully that
will go away because as she’s started to learn that she can draw,
whereas before she’d just scribble on the wall, she’s quite happy
now to go and get a piece of paper and to draw on the piece of
paper, drawing on the walls has gone away, but the new problem
is, as I mentioned, that if she finds a cup of anything she’ll pour it
on the floor ‘cos it sounds nice and that’s what they’ve done at
school, so I’ve got to talk to the school about that.

A: So you’re less likely to go out to your friends as often as
before? Or do you force yourselves to go out and just worry
while your there?

S: Well, we just do it, mainly ‘cos it’s good for Chelsea,
what we have found is . . . what we were told originally was that
autistic children don’t like new settings, and what we found with
Chelsea is that that is the exact opposite! We get more of a
reaction from her if she is in a new setting, because she isn’t in a
familiar setting with the same things that she knows what to do
with, it’s got to be something new, so therefore she’s got to
communicate with us even more, ‘cos she’s got to ask for things
even more ‘cos they’re not there and available for her, so what
we’ve found is that it’s very good to do that, and even more so
on holidays, we try and take a lot of short but lots of them,
breaks, if we can afford them, but of course during the non-term
time they’re very expensive but we’ve found they’re very good
for her.
A: Excellent. So you're actually doing more of that kind of thing, short breaks, than if Chelsea didn't have autism?

S: Well, we might have ventured abroad and things like that, but with Chelsea we just couldn't at this moment in time.

A: So when you choose the holiday it's got to be...

S: It's got to be suitable for Chelsea. I mean the big one of that, it was lovely, it was two years ago, and as I've told you Chelsea undoing the door is fine, we went to Great Yarmouth and three days into the holiday Chelsea found that she could undo the caravan door, and we'd found no way of locking it, so you can imagine, at night, every time you heard a bit of noise you thought "is that Chelsea getting out of the caravan?!", we went home two days early, 'cos we just weren't enjoying the holiday and we were absolutely dead beat. So there's an example of... you then know that the next time you've gotta have something that you can lock. So, you do tailor the holidays toward her, we do bear F in mind, but she's quite happy when she's got a playground, a swimming pool and that's a good thing about Chelsea, she can swim, age of five, last week she even told us so, "I swim!".

A: Haha.

S: And with friends. Going to new people's houses is a nightmare. But the only places that we really don't feel any compunction about is the two sets of parents. That's their problem. They're grandparents and they've got to put up with their granddaughter, and if they can't de-Chelsea their house properly then that's tough luck, and what we do is let them follow her round when we go there!
A: So you get a good break when you go round there?

S: Exactly.

A: Have they adjusted quite well to that?

S: Um. Yes they have. It's, like we were talking about routines with Chelsea and you get a rapport with the school and we work the same, we'll the grandparents can't quite do that... they try very hard, they do use what I call pigeon English to her and um, and they just cater for her, they know that Chelsea is coming so they... they have to prime themselves for it and that's fine. We've never let Chelsea stay over their though yet, we've let F stay. And there's a big one this year, we're going away for a weekend, the first time ever in six years.

A: That's quite a change.

S: We've never been away and left the kids before. We probably would have done if it wasn't as it is. We're concerned.

A: Is that mostly a regard for safety?

S: Um, not only safety, it's Chelsea, I'd like to tell her that we've going away for two days I will see you on Sunday...

A: And...

S: And for her to understand that we've just gone away for two days and we will be back on Sunday, we still haven't been able to do that with her, but what has happened is that she gets on the bus to go to school everyday. Now, obviously she doesn't
know that she’s coming back ... and didn’t know she was
coming back the first time she got on the bus, she does now, ut
she accepted that, so we’re hoping that the fact that we’re not
going to be there for a couple of nights ... is just an extension of
that really.

A: Um. I hope that goes well.
S: Yes. It’s our 10th wedding anniversary.
A: Congratulations! And I hope you don’t feel stressed all
the way through.
S: I’m getting drunk!
A: Fantastic. So still thinking about the social aspects, do
you think that other adults perceive you differently ‘cos your child
has a developmental disorder?
S: Um ... think of us as parents differently? Yeah.
A: Of you specifically.
S: I’d say yes they’d have to. It’s again it’s the early days
that were the most difficult time where they didn’t understand
why we were letting Chelsea do what she was doing and most of
our good friends have now been educated in the ways of Chelsea,
which of course helps a great deal, so, but I’d say that’s the only
aspect that they would treat me differently by.
A: How do understand that, what sense do you make of that?
S: I think that most of them, find it, well, originally would find it difficult, they've all got children that have . . . gone down the normal path that children would go down, and they found it very difficult to accept that this child . . . and what you have to bear in mind is that Chelsea is also 1 metre twenty tall, so she's the normal size of a six to seven year old at this point in time, and people's perception of her is that she should be able to do more, and she should be conforming a great deal more, and they struggled with this to start with, really struggled.

A: So it's kind of a mismatch between what they expect her to do and act like, and what they expect you to expect from her, . . .

S. Exactly, and you don't judge a child on what it does, you're judging the parent at that point, because it's not up to the child to know what to do, it's up to the parents to have told the child what they should be doing. And um, it's like um, it's never a poor student it's only ever a poor teacher isn't it!

A: Do you think that accounts for some of the feelings of uncomfortableness that parents report in say . . . going to the supermarket?

S: Yeah.

A: 'Cos it's more of a comment on the interaction of the parent and child than about the child itself?

S: That's right. I mean I don't think people are judging the child, I think they are judging the parent. And, the number of times you end up saying "She's autistic", (laughs), totally wrong, but you do.
A: So how have you come to not worry about that?

S. Um, personally, well you see, I don't think you can teach yourself that. 'Cos my wife can't. And I don't think anybody can. You either have to be grown to that, or used to that, and I am, or you're not.

A: So it's a personality . . .

S: It's a personality thing. I mean, things like that never ever worry me.

A: Okay. How do you consider that role of a father of an autistic child to be different from other family members?

S: Well. Inside of the family, as to my wife and myself I think I have a different role, I have a far different role with F than X does with F, but I don't feel that's the same for Chelsea, I feel we have the same role, mainly 'cos it's the . . . I'm getting back to the routine and the way things are done, everyone has to do the same, or you're giving her the wrong messages, or that's what we try and do in any case. So I don't feel my role is any different, only the fact that I do the baths all the time, and , or , I do this, it's just a matter of timing or convenience, but I wouldn't call those . . . .

A: So they're not fundamental differences . . .

S. No. They're just practical differences. But I'd say that I do deal, I deal with F differently than X deals with F.
A: In what way?

S: Um. I suppose it's a bit... it's like this old business, "Oh, I'll tell your father you did that". And its, more up to me to lay the law down than it is my wife, because they feel like they need a comfort zone to go to and if you're both billed as ogres they get a little bit alienated... so.

A: So you're the bad cop!

S: Exactly. You just, it's all tongue in cheek stuff, but she has to understand that it isn't perhaps tongue in cheek.

A: But for Chelsea you're trying to be a coherent as possible so the rules are the same the reactions are the same...

S: Yup.

A: Would that be obvious to other people?

S: Um. I would say, probably yes. I'm looking at it from the grandparents' point of view, and I would say that it would be obvious that we do have those different roles for each of the children. Our friends, I'm not sure it would be, 'cos we, we see like each set of friends once every six weeks, so they're never gonna build that picture up in the time that we see them. Only from the fact that we follow them round in the house all the time you know.

A: So, are there any differences between how you are and how your wife is with Chelsea?
S: With Chelsea. Um. Only from character traits 'cos I'm an up and down person, I get angry very quickly but come down very quickly, but my wife is totally calm, and she's calm with the children, whereas I'm a little but more "come on let's get up and do things". So, but that's not really what you're after is it.

A: I'm just after anything you want to bring, so that's cool. Um. Do you feel that having an autistic child has put a specific stress on your marital relationship with your wife X?

S: No. I think it makes it stronger. It will do one of two things, it'll drive you apart or it'll make you stronger.

A: When do you think that stress is most important, when is the critical time if there is one?

S: I, um, I don't understand the word stress, I'm not a stressful person, I don't find things get to me that much, so I find it difficult to relate stress in a marriage . . . I think there are other things than autism that will cause more problems than that . . . playing golf too much is one of them! But no . . . but no, I would say that if anything it's gonna do one of two things it'll either tear you apart because of the different views that you're gonna have, I mean you might have one wanting LOVAAS and the other one thinking well no, [Autism Nursery] is good enough, but we're pretty practical the pair of us, and as I say, we've decided that we're gonna go with the [Autism Nursery] line and the pair of us are working with them to help Chelsea.

A: So in a way it's provided a structure?

S: Well, if you look at a lot of marriages, how many marriages are there where the two people have a great deal in
It's usually they're complete opposites, so they can compensate for each other. Having Chelsea and having to deal with her a great deal has probably been one of the major things that me and my wife have in common. 'Cos had they both been normal children then I'd have been the ogre on both sides! So, we'd have totally different roles at that point, but at the moment, it's like a really . . . we enjoy going out seeing different places, but that's not what you'd call hobby type things, I know it's not nice to call autism a hobby but it's something that we both have in common that we really both sit down and talk about and try to deal with. So, I would say no, if anything it's made ours stronger.

A: Okay. These questions are about coping and support in a wider way. How do you feel that you've coped with the varied challenges that parenting an autistic child has faced you with? On a personal level, we've covered this a little before, but I wondered if there was anything else about how you've coped?

S. Um. I think, we've covered it really. I like problem solving, I'd rather not have had this problem to solve I must admit, but um. . . the other thing is that I'm the up and down person, so at the beginning of each problem when it arrives I'm the worst person.

A: Right, and?

S: My wife is the best person 'cos she's quite calm. But as the problem needs to be solved, I get better at solving the problem.

A: So, you have a little initial "ah" and then calm down and get on with it?
S: Yes, I had something in mind but it's just gone. Oh well, it'll come back.

A: Okay, no problem. What kind of support have you asked for in the first couple of years?

S: We haven't really asked for any. I don't actually think . . . well, let's be fair, we had two very good sets of grandparents and without those this problem would have been ex-fold more difficult.

A: Right, so the support you've got from both your sets of grandparents has been key?

S: Yeah. We've got a lot . . . autism is quite a tight knit family, so the other parents of autistic kids stick together and you make new friends through it, and um, I've seen the ones that haven't got local support and you feel very very sorry for them. And you can see that they really do struggle, and that that's where you need much much more help. But, every now and again if we can say "You've got Chelsea for the day" . . . and we go out for the day . . . it's fine, you've got that little bit of time away from it where someone else is dealing with the problem. But, I mean, it's just what you have to do really isn't it.

A: Um (pause) we've covered a lot, I think we'll move on. This section is about your relationship to services and also the process of assessment and diagnosis.

S: Too slow!
A: Too slow. That’s spooky, the first question is how would you summarise the process of assessment and diagnosis?!

S. Well, no, I suppose that’s not strictly true, it was the . . . the period of assessment and Chelsea being diagnosed was excellent, it was, P saw her, then M and L saw her very quickly after that, and then diagnosis fine. What we did find was the next five months nothing happened. Not a thing.

A: How long did it take from you having concerns about Chelsea to getting to see the right people?

S: Quick, very quick. Well, reasonably. The community nurse came at 18 months and immediately had concerns and said get her in to a local nursery, so the local nursery took her immediately, get her playing with other children and whatever, and I’ll get you an appointment at the hospital. And that was the start of it. And we saw P within two months of that. And then we went through the usual tests, is it hearing, so she had hearing tests, I forget, there was another test, then there was blood tests, went through all of these and the diagnosis from there was oh, within 4 months, very very quick. And, then this period where nothing happened. And um, we were saying well can’t she come to [Autism Nursery]? “Oh, the place is there, we’re waiting for the paperwork to be filled in” and it took 5 months at that point and I think they were a wasted 5 months. I really thought they were.

A: That must have been quite frustrating.

S: Yeah.
A: ‘Cos you’ve got your answer, and now you want to do something positive about it?

S. Yeah. It was still quite worrying from the point of view that [Autism Nursery] was only an assessment centre, at that point, there was no guarantee that she’d get anything other than being assessed. But, I think [Autism Nursery] evolved very quickly during that period and it was obvious that the children from the reception year had nowhere else to go, so they had to produce something for those children. The other problem that we did have was that, um, it’s probably not their fault, but in the early days it was two afternoons a week and oh, um, yeah, you can have another one then . . . all very very vague. But I think to be fair, it was all to do with resource, they didn’t know what they could offer people. You know, we organised our life around Chelsea being there two afternoons a week, and then the next week they said “oh, she’s got the full day and another three days a week” and you’ve got to go and rearrange all the things that you’d arranged, ‘cos we paid for music therapy for her, which she really reacted to really well. But, that was the only criticism in the early days. But that’s minor, and I think that’s improved a lot.

A: How do you think that your experiences of the process of diagnosis and consulting with health services is different for fathers than for mothers, if at all?

S: Um. I think really . . . it’s (Pause). How would you put it . . . um there is a little bit of stigma attached to having a child with autism, and

A: Where does that stigma come from?
S: No idea. I think it's getting less and less 'cos autism is in the press a great deal more now, and it was always thought before that it was caused by neglecting your babies, leaving them in the pram etc. But that is going to effect you. And whereas it did affect my wife it didn't effect me. All it made me feel was... right what are you going to do about it? And it was quite funny, one of the first questions the SLT put to us was “are you going to accept that she is autistic?”.

A: And how did you want to answer that one?

S: Well... “Yes! You're the professional”. But some people don't want it because it is literally, at the moment there is no cure for autism and you have it for life, so that's on your medical record, now some people may not want that, but mine is “yup, now what are you gonna do for me?” And I say, the 5 months after that were the problem.

A: Have you found that you're treated differently by professionals than your wife is?

S: No. The only maybe thing is that they are a little bit more sympathetic to the women. But that's because of the nature of life I say, they are more likely to be ‘upset’ about this type of thing, I presume some men are, but would have said very few, so not treated differently really in any other way. Most of the, in fact it's a rarity talking to you, 'cos you're probably the first male I've spoken to about this problem.

A: How does it feel to be involved with services which are so female dominated? How do you think it affects Chelsea?
S: I don’t really know how it affects Chelsea. But I can understand it, women are slightly more tolerant and slightly more sympathetic which is what we just talked about towards problems like that, so perhaps that’s why the majority of them are females. There’s a guy here though who came in and gave a lecture, but everyone else is a lady. It’s a very female type environment. It’s quite funny, no I come to think about it there’s only the manager of the school who I can think of who’s a man.

A: O.K.

S: Oh, and of course Chelsea is a bit of a minority being a girl with autism, what a one in ten?

A: Do you think that’s affected the process of diagnosis at all?

S: No, I think it didn’t affect their decision, but I think it may have an effect on the next school, the next choice. ‘Cos you get the impression from the schools that they do want a balance . . . and there are very few girls with the problem. But we also have the problem that although they won’t admit it, take entirely different types of children. L.B. takes the more able children and F. takes the more severe ones.

A: And that hidden a wee bit?

S: Yeah. If, you talk to the teachers there, they won’t admit that. When they walk you round the school they say “Your child will leave here with one GCSE” but Chelsea won’t leave nowhere with a GCSE. She’ll have a good knowledge of life, I hope, but .
so really what they’re saying is that your chances of getting her in are very very slim.

A: So is that a bit of a characteristic of your experience of services? That they say one thing but that there may be other things going on?

S: Yes, I think there are hidden agendas all over the place. And, if it’s, it’s apparent to me. You look at [Autism Nursery] and think “well done [County], you’ve done something about this autistic problem” and then you find out that it may be to do with LOVAAS, ‘cos they’re getting hammered by paying for LOVAAS! Hidden agendas everywhere. What the heck, I don’t care, but it’s a bit annoying. With the authorities, the thing you’ve got to try not to do, and again, in the first meeting we had the lady gave us some very good advice, is try not to battle with them too much, the resource has to be shared amongst a lot of people, don’t expect the earth all the time, just try and get what you can out of the authorities, ‘cos if you get their back up you’re gonna get nothing. Good advice. What we have also noticed, is that some geographical areas have much better services than others, like, Chelsea is coming up to school age and so the Paediatricians start to back off and the Educational Psychologists take a front seat, if you’ve got an Ed Psych with an interest in autism, you’ll get a much better service than with an Ed Psych that just prefers to deal with other problems. What we found is that we’ve only seen them 3 times. Once in the original interview and twice at reviews. Whereas we’ve got other friends who’s Ed Psych has been to their house many times, but in fairness that one has an interest in autism.

A: So some of it may come down to the individual professionals that you meet?
S: Yeah. Yeah, and I’ve been told that they are generally over stretched anyway, so they’re aren’t going to be able to spend the time.

A: Is that a little frustrating?

S: It is so. I hope we’d see some more of them, she goes to panel soon, to decide where she goes to school, and I assume they’ll be there, I guess they’ll submit a report, but that can’t be based on anything they’ve seen, ‘cos they’ve only met Chelsea for ten minutes and hasn’t been round to see us beforehand. And that’s a worry ‘cos that board determines her next five to ten years.

A: So there’s a concern then that services aren’t giving Chelsea the best they could?

S: It’s very difficult to criticise [County] though, when you look at [County] and [County] and [County] where they’ve got virtually nothing! It’s not enough, but when you’ve got people moving into [County] so they can use the autistic facilities, it kind of says what [County] is giving, so I don’t think it’s enough, yet I know that it’s a great deal more than what a lot of other people are getting. So.

A: An uncomfortable position to be in then?

S: It is. And I’ll be much more comfortable after the board meet and I get a right answer!
A: OK. If a male friend suspected that they had a child that had autistic traits, what advice would you give him based on your experience?

S: The first thing they've got to do is go and see a Paediatrician (Pause), and I think that it's very easy to see autistic traits in everybody now, once you've got them in your head, you know what they are, it was the same with X's brother, he had concerns and the first thing we told him was that, you must get an appointment to see a Paediatrician, and that's what they did. And do you know what [County] offered them? Half a day a week. It was a person coming to your house for half a day a week. And it just wasn't good enough, just wasn't good enough at all. How are you going to install PECS in half a morning a week! Hmm.

A: Is there anything that you think you could advise fathers on with regard to coping with stresses and strains?

S: I think, the advice would be to go to the first meetings and the only thing that you can be with the kids is patient ... you know that tomorrow you aren't going to see a big change from yesterday or the day before, so you've got to just expect this slow progress, and not to be too aggressive with the system, you have to learn when to be aggressive and when to be patient with the system. The only time I felt the system let us down was the 5 months we had to wait to get her into the service after the diagnosis which I felt was a wasted 5 months. She should have been there, we went to the school several times, the place was there, why on earth wasn't she there, that's exactly what the staff at [Autism Nursery] were saying. They were looking forward to getting their a girl in the nursery as well!
A: Um.

S. The [Hospital] ran a group for parents of newly diagnosed autistic children which was very good 'cos we made a lot of friends through that and a lot of them have gone on to [Autism Nursery], and I think you can give people a lot of support during it, X stays in touch a lot more than I do, there's one lad who goes to [School] and his mum really struggles for support locally, but X stays in contact with her, goes for coffee with her every now and again, and let the kids play with each other.

A: So it's a parent's of children with autism subculture?

S: It is. It's a little club. We've got friends G and F we see on a regular basis, and X goes out with F once a week.

A: So it's really quite important then, that informal contact?

S: Yes, I think it is, I think it really is. And, it's become very much more important now, 'cos before we used to go and pick Chelsea up and you'd learn what she did that day, what she'd learned now, and all the things she's capable of, now she comes home on the bus . . . so that contact doesn't exist anymore. So other people who do go to the school regularly, they can feed us information, although you do have a diary that comes home with her, it's still nice to hear those other things or whatever. I still go once a week to the school to pick Chelsea up, 'cos we can't get to swimming unless I pick her up and go from there. So I do go once a week to have a chat to them. Now we've got to talk about the pouring out problem this week. It's funny, 'cos Chelsea unlike a lot of the other children doesn't have a problem with textures and the like, and they said that she went into the
cubbyard and spilled the flour all over the floor, so they made a
game of it, drawing patterns in it, but if she did that at home I'd
be gutted . . . and that's another of those little ones that are
virtually insoluble, one of the ones that will go in time, where
she's got her routine and the next step will be a routine here and a
different routine is acceptable at school. Now I don't know how
many years off that is . . .

A: But that's the goal for you?

S. Yeah and at the moment I don't think it's possible to
solve. It's too early, she's just not capable of that, so we'll just
have to wait for that, but it still doesn't hurt to make the school
aware . . . by the way, she has an excellent teacher there.

A: Good. Um. Just a question about [Autism Nursery]
specifically. In what ways do you think [Autism Nursery] could
better address the needs and wishes of fathers of children
attending the centre?

S: I'm not sure to tell the truth. I'm think I'm getting quite a
good service out of [Autism Nursery] at the moment. And um . .
. . it's . . . I can understand that there's a certain amount of fathers
that really never go to [Autism Nursery] . . . and that they may
have some issues which . . . that you may be after, but because I
am more involved with it, I'm also involved already, so I don't
feel I need anything more.

A: OK. Thanks. Do you have any questions, or do you think
there are any questions that you think I haven't asked? Or areas
that I've been completely blind to?
S: From your point of view would be nice to ask in three years time when Chelsea is um . . . grown, and what she does is a great deal more, and if you asked me those questions in three years time would you get the same answers . . .

A: What do you think?

S: I don't think you would. I think that again she'll be at a different school, um . . . hopefully she'll be at a different level of understanding, and that by then I may even have that rule and 2 routines in place and that will change my life!

A: Really?

S: Yes, most definitely. To have this acceptability in one place and not in the other . . . where you can do these things and why you can do them. 'Cos even I broke the rule, 'cos in the bath, she's got things and she can pour things and she likes to, it's acceptable to do it there, but not downstairs. So I'm hoping that I'd be able to say oh yeah we've been abroad, and oh yeah she stays with the grandparents every weekend . . . again though I think there'll be other problems that happen as she's growing up, on the darker side of things . . . not being able to communicate her feelings to us properly . . . so it's all going to be ebb and flow, and that's what it is at the moment. Look at the next problem round the corner.

A: Very practical.

S: Yeah. It'd be nice to do the interview again.
A: If we were going to set up a group about the more practical aspects of how the system works and how things go usually, when would be the best time to give that information?

S. I think you have to have it ASAP. For us it was addressed by the meetings at the hospital where they got all these people from different to talk to us about all different aspects and treatments etc. But most of the ones who were there, especially the women seemed to have already read books about stuff . . .

A: So information in a way isn’t the most important thing?

S: No. Like, we were on the web, we were well armed with information, and I think there aren’t many parents of children with autism who aren’t well armed in that way.

A: So what you’d value more is?

S: Practical ideas and support about what we can do to teach them. The sort of stuff that isn’t in the books, isn’t on the web. And you need that before you get the assessment. There is a problem of course in that they don’t know at that stage what routines or ways you should be using with your child . . .of course we’re all trying to find ways to communicate with Chelsea and it was good to have some ideas given to us about that early on about what we could do with her when she was at home, rather than what they were going to try with her. And I guess that PECS (Picture Exchange Communication System) is definitely the flavour of the month at the moment.

A: Great. Thanks for that (Short debrief followed).