

**AN INVESTIGATION INTO THE WAITING LIST EXPERIENCE –  
EXPLORING PARENTS VIEWS OF CHILDREN REFERRED TO A CHILD  
AND ADOLESCENT MENTAL HEALTH SERVICE.**

**by**

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## DECLARATION

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## **DEDICATION**

This thesis is dedicated to all my family for their patience and understanding, my colleagues for their support and encouragement, my friend for her kindness and generosity and my clinical supervisor for his belief in my capacity to become.

# INDEX

ABSTRACT .....	1
Aims.....	1
Method.....	1
Results.....	1
Conclusion .....	1
OVERVIEW.....	2
THE WAITING LIST PHENOMENON: REVIEW OF THE LITERATURE .....	5
LITERATURE REVIEW .....	6
Introduction .....	6
Method.....	6
Definition of ‘Waiting Lists’ .....	7
The History of Waiting Lists .....	8
The Nature of Waiting Lists – a Back Log of Untreated Patients? .....	10
The Mechanism of Waiting Lists – a Control for Consultants.....	12
The Power of Waiting Lists – Central Hierarchical Control .....	14
Present Day Reforms .....	18
The NHS Plan 2000 – Cutting Waiting for Treatment .....	19
NHS – Outpatient Waiting Times .....	21
The NHS Improvement Plan 2004 .....	22
Demand and Capacity .....	25
Quantity versus Quality – Service User Perspective.....	26
Quantity versus Quality - Media Reports on Patient Experiences.....	28
Evaluation of Present Day Reforms.....	33
Academic Research – The Answer?.....	35
Waiting Times – the Future?.....	39
Introduction to Research Paper .....	40
RESEARCH PAPER.....	44
An Investigation into the Waiting List Experience – Exploring Parents Views of Children Referred to a Child and Adolescent Mental Health Service.....	44
INTRODUCTION.....	45
Non-attendance – the Cause? .....	46
Non Attendance – the Reason? .....	47
Non-attendance – The Way Forward?.....	49
Conclusion .....	50
The Present Inquiry .....	51
METHOD.....	54
Rationale and Aims for the Study .....	54
Methodology .....	56
Ethical Approval.....	56
Methodological Rationale .....	56
Qualitative Research .....	57
Grounded Theory .....	59
The Researcher.....	60
Participants.....	60
Selection of Participants .....	61

Table 1 Example of Referrals in Purposive Sample following	
Exclusion Criteria .....	62
Measures.....	63
Procedure .....	63
Analytical Strategy.....	64
RESULTS.....	67
Figure 2 Description of Main Themes and Related Subcategories.	69
Description of Model .....	70
States of Self.....	70
The Passive Self .....	71
The Active Self .....	72
Movement between the Passive Self and the Active Self.....	72
Need for Answers/Diagnosis .....	73
How the Professional is Viewed .....	73
DNA Intentions .....	74
Linking Categories and Central Relationships.....	74
Definition of Themes and Sub categories.....	75
Theme - States of Self .....	75
Self as alone .....	75
Self as abandoned .....	76
Self as not valued.....	76
Self Blame.....	77
Theme - The Passive Self.....	77
Stress on family system .....	78
Lack of Support Networks .....	79
Disempowerment .....	80
Helplessness.....	80
Need for containment.....	81
Resignation .....	82
Lack of knowledge .....	83
Negative Waiting Experience .....	83
Theme – The Active Self.....	84
Empowerment .....	85
Search for Knowledge.....	86
Developing own intervention .....	86
Positive Waiting Experience.....	87
Theme - Need for Answers/Diagnosis .....	88
Need for Confirmation .....	88
Need to Parent .....	89
Need to Remove Self Blame .....	89
Theme – How the Professional is Viewed.....	90
Professional as Expert .....	90
Expectations of Professional .....	91
Theme – DNA Intentions.....	92
Hope.....	92
Desperation.....	92
Concluding Comments .....	93
DISCUSSION .....	95
States of Self .....	96
The Passive and Active Self .....	96

How the Professional is Viewed.....	99
Need for Diagnosis .....	100
DNA Intentions.....	100
Implications for Service Delivery and Clinical Practice .....	102
Service Delivery.....	102
Clinical Practice in Relation to Counselling Psychology .....	105
Limitations.....	106
Reflection.....	110
A CRITIQUE OF THE RESEARCH PROCESS .....	112
AND REFLEXIVE PRACTICE.....	112
My Choice of Research.....	113
How the Challenges were Met .....	113
Difficulties I Faced .....	117
The Contribution of this Research to the Existing Body of Literature .....	118
Conclusion .....	119
REFERENCES .....	121
APPENDICES .....	142
APPENDIX I.....	143
The Framework of a Four Tier Service.....	143
APPENDIX II.....	146
The Relationship Between Referral Rates, Waiting Times and DNA .....	146
Rawlinson and Williams (2000).....	146
Ref .....	147
APPENDIX III.....	148
Example of Semi-Structured Interview Questions .....	148
Semi-Structured Interview Questions.....	149
APPENDIX IV .....	150
Example of Information Sheet.....	150
APPENDIX V .....	153
Example of Reply Slip .....	153
APPENDIX VI .....	155
Example of Consent Form.....	155
APPENDIX VII .....	157
Example of Transcript Analysis Line by Line Coding, Formation of Sub Categories and Central Relationships.....	157
APPENDIX VIII .....	159
Example of Building Subcategories.....	159
APPENDIX IX .....	161
Notes for Contributors .....	161
APPENDIX X .....	162
Copies of Letters of Approval from Ethical Committees .....	162



# ABSTRACT

**Aims:** The purpose of the qualitative study was to gain insight into the way parents experience and manage the waiting process following a referral to a Child and Adolescent Mental Health Service. The aim was to use the information for future service delivery and therapeutic engagement.

**Method:** 6 parents whose child had been referred to a Child and Adolescent Mental Health Service and had been waiting for more than eight weeks were recruited using a purposive sampling method and participated in a semi-structured interview. The interviews were transcribed and analysed using the principles of Pidgeon & Henwood's (1992) grounded theory techniques, facilitating the development and refinement of a theoretical model.

**Results:** The resulting model highlights the waiting experience as fraught by loneliness, abandonment and self blame resulting in an interchanging role of being active or passive and the subsequent cycle they subside into. Some parents use the waiting time effectively by searching for their own answers but may eventually become passive following a belief that their parenting is insufficient. The disempowerment and self blame that is perpetuated through waiting intensifies the parents' helplessness and results in a wide disparity between a negative self view and the idealised view of the professional.

**Conclusion:** This study described the difficult experiences parents face while waiting for their child's initial appointment. Parents need to be offered support, information and empowerment while waiting with ongoing communication from the service. Recommendations for future service and clinical delivery are provided.

# OVERVIEW

This thesis begins with an investigation into the ‘waiting list phenomenon’ that is a matter of concern for most NHS clinical departments. The literature review critically appraises past and current literature which examines the predisposing, precipitating and maintaining factors that contribute to long waiting lists. An evaluation of historical literature suggests that waiting lists have been an important factor in measuring both the effectiveness and resource requirements of the NHS. Long waiting lists have been identified as a ‘mismatch between supply and demand’ and *ear-marked* funding for waiting list initiatives has promoted an internal dynamic resulting in an increase of referrals.

The literature review goes beyond (take out-the peripheral belief of the) ‘mismatch’ theory and appraises theoretical positions regarding the existence and purpose of waiting lists. In relation to this, the fundamental shift to de-centralise power away from central Government is deliberated upon and it is argued that this de-centralisation of power is equated to the de-centralisation of blame. This is evidenced by the change in policy from offering extra resources for waiting list initiatives during the time of centralised power to imposing financial penalties and punishments following de-centralisation. It is argued that whilst imposed sanctions remain, the claim that it is de-centralised does not hold. All that has been decentralised is blame, and control remains with central Government.

In the NHS Plan (2000) the Government proposed a plan of staged reduction to cut waiting lists. Although initially reported figures since 2000 suggest the plan is being

met, (GAP) critical consideration is given to the reported improvements and how quantitative information is gathered in relation to published figures. The argument which suggests figures are not reported to reflect the patient's journey through their health care and therefore are not indicative of their true wait from visiting their GP to treatment end are discussed. Media publications are included that highlight the ongoing concerns about waiting lists and the patients real experiences of them. This suggests that the reduction in waiting times has not been as successful as claimed, as the problem though effectively concealed, remains.

The review concludes with an overview of a qualitative academic study that goes beyond the facts and figures and examines the day to day running of an NHS department to explain the maintenance of high waiting lists. It extends previous literature in offering a systemic explanation of the waiting list experience. Questions are asked regarding the apparent failure to build waiting list reforms upon academic research whilst acknowledging the dearth of published literature addressing this issue. Recommendations are therefore given to commission further psychological research especially from counselling psychologists given their humanistic and existential-phenomenological philosophy and experimental behavioural scientific roots, which could inform the future political agenda and policy making.

Having considered waiting lists as a wider issue the literature review concludes by introducing the specific related area for the research paper which explores the waiting list experience of parents whose child has been referred to a Child and Adolescent Mental Health Service (CAMHS) An explanation of the tiered approach introduced to

CAMHS (1995) is given to provide context and introduce the reader to the subject of inquiry.

The research paper identifies from current literature the dynamic between long waiting lists and non-attendance for initial appointments. The aim was to understand how parents whose children have been referred to a Child and Adolescent Mental Health Service experience the waiting time in a bid to inform future service development aimed at supporting the family throughout the process, and encouraging a positive therapeutic relationship at the outset. Embracing a qualitative approach and using grounded theory as an analytical tool, the research goes some way to understanding waiting lists from a potential service user's perspective which no previous research has addressed. To encapsulate the themes that emerged from interviews a model was developed which demonstrated dominant themes showing how parents move between activity and passivity during the waiting period. The model illustrates that there is a wide disparity between how the parents view themselves, and the way they view the professional. In conclusion, the research implications for service delivery and clinical practice are discussed, along with the limitations of the study and recommendations for further research.

Finally a critical account of the research process from a reflective and personal position is given to highlight personal and professional growth and provide insight into what informed the choice of research, how the challenges were met and how the findings add to the existing body of literature.

# **THE WAITING LIST PHENOMENON: REVIEW OF THE LITERATURE**

# LITERATURE REVIEW

## **Introduction**

One of the political aims encapsulated in the Government's manifesto pledge was to reduce waiting lists by treating more people (Hamblin, 1998). Department of Health figures on current waiting times for inpatient and outpatient care suggest that this has not been achieved in relation to the acceptable levels identified in the Patient's Charter (Department of Health, 1991).

This review examines existing literature of waiting list phenomenon, including the history and nature of the waiting list problem, and the implications for referred clients and service delivery. Much of the academic research examined on this issue relates to the 1980s and early 1990s when waiting lists were seemingly a topical debate nationally and internationally. Given the increasing emphasis on length of waiting lists in many NHS Trusts it is surprising that there are no recent papers that specifically address the issues (Rawlinson and Williams (2000). This review therefore considers academic research to explain past and current trends in addition to political papers and media publications, which underpin the present research inquiry and consequent methodological reasoning.

## **Method**

Literature searches were conducted through a variety of media. Database searches using Psycinfo, Medscape, Medline, Cinahl, Assianet and Swetwise were undertaken

for the years 1940 to 1995. Further to this a full internet search was utilised through internet search engines with particular attention given to sites such as The Department of Health, Healthcare Commission and those with political interests in the area of study including media News websites. Keywords used in all searches were waiting lists, waiting times, initial appointments, out patient resources, did not attend, non-attendance, no show, failure to attend, mental health services, Child and Adolescent Mental Health Services, parents experiences, service user experiences, waiting time surveys, waiting time figures, waiting time outcomes, improving waiting times, improving waiting outcomes, qualitative research, grounded theory, counselling psychology, therapeutic engagement, therapeutic alliance. Books and articles were also identified through the University's OPAC online catalogue. Further articles were identified through a hand search of the reference section of each paper obtained until the search was exhausted. Articles were obtained through accessing the on-line full text service, journals and books from the University of Wolverhampton Learning Centre, the internet or ordered from the British Library holdings. Articles were included if they contributed to the review in question and were fully referenced to their original source.

### **Definition of 'Waiting Lists'**

Waiting lists in the context of the present discussion are defined by the writer as the number of patients waiting for treatment in the National Health Service (NHS). The same definition is used to define both waiting for inpatient and outpatient treatment across the specialities of care provision. Frost (1980) related waiting lists to an equilibrating mechanism contending that when a price below the equilibrating level has been fixed by some agency, such as the Government, the available supply will be

rationed by queuing. Further positions define waiting lists as a backlog of untreated patients (Doran, 1990), a gatekeeper to NHS services (Jessop, 1989), a control mechanism for Consultants to limit their own caseload and promote their popularity (Frost, 1980); and a bureaucratic discourse to enable the management and control from a central hierarchical NHS (Hughes & Griffiths, 1999).

### **The History of Waiting Lists**

Historically, waiting list figures have long been used to measure both the effectiveness and resource requirements of the NHS. Waiting lists have increased since the inception of the NHS, with recorded figures showing approximately 450,000 patients waiting in 1948, 688,000 patients waiting in 1987, increasing to 1,262,300 patients waiting in 1997 (Department of Health & Social Security, 1987; Tudor Edwards, 1997). The number of people and length of time waiting have been extensively used as performance indicators (Radical Statistics Health Group, 1995) and have consequently encouraged policy initiatives to reduce waiting times with earmarked funding to ensure their effectiveness (Department of Health, 1992; Newton et al., 1995).

Frankel (1989) argued that the waiting list phenomenon distracts attention from an appreciation of the real nature of the problem. He stated that to gain an understanding of the natural history of the waiting time problem it is necessary to look beyond resources and management to public responses of waiting time conditions and the priorities set by professionals. In relation to the former, Frankel (1989) found that certain medical conditions have elicited public sympathy, such as cardiac surgery and child terminal illnesses. In the latter case public appeals for funding to support research or the purchase of medical equipment have benefited the treatment process and



consequently waiting times. Less public interest has been given to problems such as varicose veins and hernias that are considered topics of humour and stereotypes with poverty and failure (Frankel, 1989). Whilst there may be some validity in Frankel's argument, he omits acknowledgment of confounding quantitative factors, such as the number of patients referred for cardiac surgery as opposed to general problems i.e. varicose veins and hernias, which may directly impact on waiting times for treatment.

In relation to priorities set by professionals, Frankel argued that it is the profession who set clinical priorities and they do so according to professional interest. To support this statement, Frankel indexed according to different conditions, the ratio of deaths/discharges with the number of papers published to indicate the level of interest each condition attracts. He found that more papers have been published for rare conditions as opposed to general conditions and concluded that the profession may find the management of certain conditions uninteresting, resulting in 'cherry picking' interesting cases whilst the remaining accrue increasing waiting times. By his own admission the crude index used by Frankel is limited, and fails to provide valid support for his argument: the index does not consider possible contributing factors for the inequality of publications, for example where there was none or little previous research, where knowledge has increased due to intense medical research, diagnosis' that have increased due to change in modern lifestyles e.g. heart problems and cancer, breakthroughs in medical science, trials of new medication or poor writing style and the bias of various editors .

Hamblin et al. (1998) recognised the disparity of measuring demand by the length of a waiting list. They argued that the Government's pledge to reduce waiting lists by

increased activity, through waiting list initiatives, are based on the misconception of unperformed work, rather than the measurement of part of a dynamic system at a point in time. Hamblin et al. (1998) found that between 1990 and 1995, the number of people seeking a GP's advice had remained constant and the number of referred patients seen in outpatient clinics had declined only slightly. However, the number of patients seen by GP's and referred to outpatient clinics had increased by nearly a third. This continued to be the case during the five year audit, which Hamblin et al. suggested is either explained by GP's recognising more people with the same degree of need, or specialists lowering their thresholds and offering appointments to less needy people.

Hamblin et al. (1998) argued that waiting list initiatives serve to promote an internal dynamic as increases in activity to reduce the size of the waiting list results in an increase of referrals. The implication is that list size and activity levels remain in equilibrium to ensure waiting times at best remain unchanged, or at worst increase.

This suggests that there may be a waiting time accepted by GP's. Hamblin et al. found that initially following a waiting list initiative, the waiting list decreases, however they explained this as a 'time-lag' between when the GP becomes aware of the state of the waiting list and reacting to the change. They concluded that historical and international evidence suggests that eventually the waiting list becomes longer than before the waiting list initiative took place.

### **The Nature of Waiting Lists – a Back Log of Untreated Patients?**

It has been suggested that NHS waiting lists are a 'mismatch between supply and demand' in the NHS (Foreman & Hanna, 2000). Successive Governments have made the reduction of all waiting lists a priority by providing earmarked funding, promoting

waiting list initiatives (Doran, 1990) and imposing penalties on services whose statistics show unacceptable waiting times (Hemingway & Jacobson, 1995; Hughes & Griffiths, 1999). Pope (1991) viewed the 'backlog theory' as an account which justifies the policy it produces, based on a rhetoric developed in response to political pressure, with the aim of eliciting action by ministers and health managers.

The launch of Department of Health waiting list initiatives in 1986 (Pope, 1991) appear to have done little to change the status quo, regardless of action taken by ministers and managers (Radical Statistics Health Group, 1995). Government politicians continue to quote statistics as indicators of successes (Conservative Party press release 751/94, 1994).

The Radical Statistics Health Group (1995) took a closer look at the quoted statistics of inpatient admissions provided by the NHS to see how their claims were justified. They found that waiting lists include names of people who have died, or have been admitted for emergency treatment, who no longer need treatment or have received treatment in a hospital other than the one to which they were originally referred. In most departments the lists are reviewed periodically and such patients are removed. However, the Radical Statistics Health Group (1995) found that the numbers of such people removed were excluded from the department's statistical bulletins when the format was revised. Arguably these figures are incorporated within the general statistics for waiting list activity, thus yielding a distorted picture. Without access to such information it is difficult to surmise just how distorted the figures are. The Radical Statistics Health Group (1995) stated that the last known figures to be published revealed a total of 219,564 patients were removed from the waiting list between September to December

1993, due to fulfilling the above criteria (House of Commons Health Committee, 1994). However, it is important to note that this figure contains a percentage of patients who were treated for emergencies. Their treatment, albeit sooner than expected still constitutes a relevant statistic of activity.

### **The Mechanism of Waiting Lists – a Control for Consultants**

Frost (1980) argued that waiting lists exist because Consultants are able to control their own workload. He found that most countries in Western Europe and North America do not have long waiting lists for minor surgery and saw this as being a consequence of patients having direct access to a Doctor of their choice, unrestricted competition between Doctors and a fee-for-service payment mode. In England Consultants are paid according to the number of sessions worked as opposed to the number of patients seen. Patients do not have direct contact to Consultants and are competing for scarce resources. In this sense Doctors and Consultants are ‘gate keepers’ as they establish who is treated and in what priority (Frost, 1980).

Historically inpatient waiting times were calculated from when a Consultant placed a patient on a surgery list (Hamblin, 1998). Numerous criticisms of shortening waiting times by delaying people’s first outpatient consultations prompted the Department of Health to start collecting statistics on how long people in England waited for their first outpatient appointment following referral from their General Practitioner (GP). The Radical Statistics Health Group (1995) argued that despite this, strategic moves were still deployed to manipulate genuine waiting times and distort statistics. They found that possibilities still remained for shortening reported waiting times for inpatient

treatment by delaying putting people on the waiting list until there was a reasonable prospect that they would not have to wait too long.

Pope & Sykes (2003) argued that a third 'forgotten wait' exists, which distorts official waiting time figures. They recognised that at present the length of time a patient waits to see a hospital specialist is carefully audited, as is the time spent on a waiting list awaiting treatment. However, they point out that a patient may not immediately be put on a waiting list for surgery due to the need for various investigations to decide the appropriate course of treatment. The wait for investigations is often considerable (Audit Commission, 2001) and not presented in statistics released by the Department of Health.

It is interesting to note that, although the Department of Health responded to criticism by collecting data of waiting times from GP referral to first out patient appointment, the two present as separate statistics even though they constitute the same ongoing care for the patient. If the third component was added as suggested by Pope & Sykes (2003), the figures would cumulate into the actual waiting time from the patient presenting to their GP to treatment end.

To further add to the dilemma of statistics being indicators of success, Armstrong (2000) emphasised the effect of excluding incomplete observations and competing events when calculating cross-sectional measures of NHS waiting times. He contended that Government statistics compound the problem by reporting two different sets of waiting times. The first set of statistics he coined 'time-to-census', which contained patients waiting at a particular date (Department of Health, 1994); the second he coined

‘time-since-enrolment’, which were electively admitted patients over a specified calendar month (Department of Health, 1996). Armstrong maintained that published summary measures use each set of data as if it represented a group of patients enrolled together and followed up until all had been admitted. Consequently, there is no knowledge of how long patients wait nor whether those who wait the longest are clinically able to.

The research cited suggests that waiting lists are substantially longer than the Department of Health statistics declare (Radical Statistics Health Group, 1995; Pope, 1991; Armstrong, 2000). If waiting lists are a consequence of a mismatch between supply and demand (Foreman & Hanna, 2000) the question arises as to how increased activity, enabled through Government earmarked funding, can possibly achieve any results when statistics do not record the true picture of need that services are unavoidably absorbing. Following this principle, ear marked funding based on statistical need would inevitably be insufficient and set up services to fail waiting list initiatives undertaken.

### **The Power of Waiting Lists – Central Hierarchical Control**

The NHS reforms of the 1990’s saw a fundamental shift, leading to de-centralised control over policy and strategy. In the move to decentralise away from central Government, hospital Trusts were given significant operational autonomy (Department of Health, 1997; Hughes & Griffiths, 1999). This move positioned the Government ‘one step away’ from the responsibility of political failure in terms of health policies and as a consequence placed the failure to meet targets with local Trusts and Commissioning bodies.

At this time the Department of Health began imposing penalties on Regional Health Authorities who had not been successful in reducing their waiting times (Hemingway & Jacobson, 1995). Previous to the NHS reforms when responsibility sat with the Government, the Department of Health ear-marked funding, which was given to services as ‘waiting list initiatives’ to encourage increased activity (Doran, 1990), whereas after the reforms the Department of Health imposed fines as a way of punishment to services not reaching targets set. The Government’s change of initiative to enforce the Patient’s Charter (Department of Health, 1991) guarantee for waiting times is arguably symbolic to the change in decentralised responsibility in the sense that encouragement has given way to punishment. Inevitably, the punishment is passed from the Department of Health to the appropriate Regional Health Authority to District Health Authorities until it eventually reaches the service ‘underperforming’ (Hemmingway & Jacobson, 1995). The consequence of this action is a service pressured to show a marked increase in activity with less resources than it had initially when struggling to reach required standards. An example of penalty enforcement was cited by Hemingway & Jacobson (1995) given by the NHS Management (1993) at which time the penalty was £4000 per patient. They recorded that in 1993 the formerly North East Thames had the highest number of patients waiting over and above the time set by the Patient Charter and were therefore fined £147,000. Hughes & Griffiths (1999) argued that central Government have continued to control and dictate the limits of permissible behaviour through the sanctions they impose and therefore cannot claim decentralisation.

*‘The image of dispersed power diverts attention away from new forms of central power, operating from more remote, less visible sites’* (Hughes & Griffiths, 1999: p.75).

Ball et al., (1997) described this new form of central direction as ‘steering at a distance’.

The Government demonstrated the extent of their control when in 1997 they commissioned ‘Regional Waiting List Task Forces’ and the ‘National Waiting List Action Team’ (announced by Mr Dobson on November 18 1997 in press notice 97/351: (DoH, 1998 [Ref: 98/139]). Of the £320 million pledged to be spent in England directly on more operations to reduce waiting lists by the secretary of State for Health in 1998, £32 million (10%) was used to create a performance fund (DoH, 1998 [Ref: 98/139]). The secretary made it quite clear that the £32 million would be used as a carrot and a stick;

*“The carrot is extra money for Health Authorities who are on target to cut their waiting lists by the agreed amounts. They could receive up to a further 10% of their initial allocation to do even more operations over the autumn and winter, while balancing likely emergency demand. Patients stand to win as waiting lists fall further”* (Frank Dobson, Secretary of State for Health, DoH, 1998:1[Ref: 98/139])

*“The stick is where Health Authorities are plainly not on target during this year. A share of their 10% will be made available to the Regional Waiting List Task Forces for remedial action. That could include sending into Health Authorities and NHS Trusts teams of managers and clinicians with a proven*



*track record of cutting waiting lists*” (Frank Dobson, Secretary of State for Health DoH, 1998:1 [Ref: 98/139]).

The quotes from Mr Dobson give a new meaning to the term ‘steering at a distance’ (Ball et al.1997) and question the level of autonomy local Trusts have in real terms. The desperation to reduce the waiting problem, possibly for political prowess and to maintain public favour is evident by the chronological change of tactics for waiting list reduction. From ear-marked money to ensure effectiveness (DoH, 1992; Newton et al.,1995), to the 1986 waiting list initiatives (Doran, 1990; Hamblin et al., 1998), the decentralisation of power to give Trusts autonomy and responsibility (DoH, 1992; Hughes & Griffiths, 1999), the imposition of penalties (Hemingway & Jacobson, 1995; Hughes & Griffiths, 1999), the 1997 commissioning of the ‘Regional Waiting List Task Force’ and ‘National Waiting List Action Team’ (DoH, 1998) and the ‘carrot and stick’ reward and punishment initiative (DoH, 1998). However, despite whichever Government have instigated the impositions whether through positive or negative reinforcement, waiting lists have continued to be a matter of concern questioning the efficacy of the forced measures placed upon them.

In May 1998 recognition was given to the fact that waiting lists were still too high and unacceptable. The Secretary of State for Health announced a proposal for tackling waiting lists through a whole system approach involving different parts of the NHS (DoH, 1998:98/190). The emphasis was on initiatives aimed at reducing the need for hospital admission by empowering family Doctors, primary care services, community health and social services, and mental health services. This approach paralleled the theoretical argument of Hamblin et al. (1998) in that the Government’s actions have

been based on the misconception of unperformed work, rather than the measurement of part of a dynamic system at a point in time. To reinforce the national drive to ‘tackle the waiting list problem at source’ a Chief Executive was appointed as a ‘NHS List Buster’ to head a new team and find ways of tackling waiting lists and spread best practice across the NHS (DoH, 1998:98/166).

### **Present Day Reforms**

In July 2000, the Government produced the first NHS Plan devised to ‘reform’ and ‘modernise’ the NHS, which they stated is a ‘1940s system operating in a 21<sup>st</sup> world’ (Directgov, 2000). The difference between this reform and previous attempts to improve the NHS was a public consultation to establish what the public wanted from the NHS. One of the main factors highlighted was the reduction in waiting times with high quality care. To achieve this, the Government pledged more money and investment over a five year plan to redesign the NHS around the needs of the patient. The Department of Health set national standards to be inspected by an independent inspectorate, the Commission for Health Improvement. The Government promised that NHS organisations that performed well would be awarded more freedom to run their own affairs and from 2003/2004 the NHS performance fund would be integrated into a system of ‘payment for results’. NHS Trusts which perform over and above agreed levels will be entitled to additional funds and therefore treating more patients will attract more money (Directgov, 2000).

### **The NHS Plan 2000 – Cutting Waiting for Treatment**

The public consultation undertaken to support the NHS plan found that the public's top concern was waiting for treatment, waiting to see a GP, waiting to be seen in a Casualty department and waiting to get into hospital. To address the initial access to healthcare the Government promised NHS direct, a 24 hour telephone helpline, would go nationwide by the end of 2000 and would develop into a one-stop gateway to out of hours healthcare by 2000. The aim was to speed up services and relieve pressures on GP surgeries and A & E. The Government pledged that by 2004 no-one would have to wait more than four hours in Accident and Emergency from arrival and admission to transfer or discharge. They promised that an average wait in an A & E department would fall to seventy-five minutes.

In relation to hospital outpatient appointments and admissions, the Government aim to reduce the maximum wait for any stage of treatment to three months by the end of 2008. The plan proposed a staged reduction of maximum wait from 18 months through 15, 12, 9 months down to 6 months and eventually 3 months (NHS Plan, 2000). This was deemed achievable by introducing on-the-spot booking systems, which according to the Plan would support making an appointment more convenient for patients and also act as a driver forcing hospitals to organise their clinic slots more productively (NHS Plan, 2000). Further to this, the Plan stated that a booking appointment system would involve GP's and Consultants sitting and agreeing which referrals are suitable for which service in which hospital. This would ensure that Consultants spend their time seeing patients who have been referred appropriately, and would have a regular scheduled stream of work. It was envisaged that waiting times for hospital

appointments and admission will be abolished and replaced with a booking system by the end of 2005. The Plan acknowledged that this would only be possible if the GP referrals remain broadly in line with the current trend in the growth of referrals (NHS Plan, 2000).

Figures of inpatient waiting times published in November 2001 showed progress towards achieving the Government targets (Health Minister John Hutton, 2001). Statistics recorded a fall of 2.3 per cent (1,000 patients) in the number of patients waiting more than a year in September 2001, which was 12.7 per cent (6,400 patients) lower than September 2000. The number of patients waiting over 15 months also fell during September by 5.8 per cent (630 patients) leaving 10,300 patients waiting, which was an overall fall of 20.7 per cent (2,700 patients) compared to September 2000 (DoH, 2001: Reference No. 2001/0529). According to the Health Minister the NHS Plan was on target to ensure no patient would have to wait longer than 15 months by April 2002. However unacknowledged, but clearly reported in the statistics the number of outpatients waiting over 13 weeks increased by 11.3 per cent (40,500 patients) since the previous quarter and outpatients waiting over 26 weeks increased by 9.1 per cent (7,700 patients) (DoH, 2001: Reference No. 2001/0529).

The Department of Health (DoH:2003/0311) reported that waiting list figures for June 2003 recorded the overall inpatient waiting list had fallen below 1 million to 992,600. This was 62,100 less than at the end of June 2002 and 165,400 less than in March 1997. In relation to outpatient waiting times in June 2003, 197 patients had waited over 21 weeks for outpatient treatment. This was 29,900 less than at the end of June 2002. The number of patients waiting 13 weeks for outpatient treatment had also fallen to

158,800, 86,700 less than recorded in June 2002. The Health Minister John Hutton stated that the figures demonstrated a continued progress in NHS waiting times and maintained the position that the health service is on course to ensure the NHS Plan target for 2005:

- No-one should wait for more than three months for an outpatient appointment by 2005
- No-one should wait for more than six months for an operation by 2005, falling to three months thereafter.

(NHS Plan, 2000)

### **NHS – Outpatient Waiting Times**

Outpatient services are one of the key pillars of the Department of Health modernisation programme because they involve over 40 million patients per annum (Healthcare Commission, 2003). Outpatient departments see more patients each year than any other hospital department. For this reason focus will be given to literature and statistics relating to outpatient waiting times.

The Healthcare Commission (2003), responsible for Audit Commissioning, acknowledged that Trusts achieved significant reductions in waiting times with nearly all Trusts consummating maximum waiting times of six months by March 2003.

However the Commission argued that the 2005 target of a maximum wait of 13 weeks is likely to prove challenging to many Trusts. The Department of Health (2005) outpatient first attendances quarter 4 (2004/2005) figures confirmed the HealthCare Commission's argument. According to the published statistics 313,033 patients were

waiting longer than 13 weeks for their first outpatient appointment and 32,076 were still waiting to be seen, 1,782 of these patients had been waiting over 21 weeks. The supporting paper outlining the data definitions (DoH, 2005) clarified that the recorded information related to referrals received from GP's only and excludes referrals from Consultants and other health professionals, self referrals and attendances at 'drop in clinics', referrals resulting in ward attendances for nursing care and referrals initiated by the consultant in charge of the clinic. To put this into context, 2,383,046 referrals were reported as received from a GP with 1,239,734 referrals headed as 'other' (DoH, 2004:q4). Therefore almost 50% of patients referred and waiting for their first outpatient appointment are not included in the Department of Health statistics. Contentiously, a disproportionate number of statistics are being reported and still not meeting the targets set out in the NHS Plan.

### **The NHS Improvement Plan 2004**

The NHS Improvement Plan published in June 2004 described major changes to carry the NHS forward to a patient-led service. The move is to transfer from a centrally directed system to a Patient-led system (Nigel Crisp, 2005; cited in DoH, 2005/4699). Nigel Crisp, NHS Chief Executive, described the changes as profound and stated they will affect the whole system and the way individuals and organisations behave (DoH:2005/4699). The belief underpinning the move is that patient's expectations for healthcare have altered and therefore it is essential to put the patients at the centre of all National Health Service reforms, which demands a major change from existing systems. However it could be argued that the patient is ill-informed of the issues influencing decisions such as: which hospital they prefer to use, which consultant they prefer to see, which operation they prefer to have, which diagnosis are they most

comfortable with, which medication they need, which hospital and consultant has the best reputation and lower waiting times etc. There is a danger that social class divisions in quality of healthcare may ensue with higher educated well informed patients making informed choices and less educated patients accepting what is left? Contentiously it may be suggested that power and hence responsibility are transferred to the service user.

In a bid to reduce waiting times and promote patient choice the Department of Health, through the NHS Modernisation Agency, established the 'National Booking Programme' (NHS Modernisation Agency, 2003). In a traditional booking system the patient is not given a choice of appointment but is sent an appointment by letter with a date and time which may signify a wait of many months. In a move towards the National Booking Programme some authorities have interposed a partial booking system. With this system, the patient is first sent a holding letter advising of an 'indicative' appointment date followed four to six weeks later by a second letter requesting the patient contact the hospital to arrange a specific date and time. This falls short of being a full booking system as the NHS Modernisation Agency state that the patient must be given the opportunity to agree a date within one working day of referral (NHS Modernisation Agency, 2002). It is envisaged that this will work by putting into operation an electronic booking system that is accessible by the patient's GP to enable on-line access to the hospital booking system so that an appointment can be booked in agreement with the patient immediately. The Department of Health set a target that two-thirds of outpatient first appointments should be booked either using the partially or fully booking system by March 2004. It was predicted that by offering a choice of dates this way, the number of cancellations and re-bookings along with the number of

DNA's would be reduced (Audit Commission, 2003). However, published figures by the Department of Health for Consultant outpatient attendances, all specialities and NHS organisations for 2004 – 2005 quarter 4 reported 321,814 (9.1%) first appointments and 1,083,448 (11.3%) follow up appointments were not attended (Department of Health dataset QMOP published 27<sup>th</sup> May 2005). This is a total of 1,415,260 (20.4%) of outpatient appointments not attended and does not include unattended outpatient appointments with other medical staff such as nurses, physiotherapists etc.

The full booking system may present as many difficulties as it intends to solve. It requires changes in the way that administrative tasks are carried out in GP practices and outpatient departments, it is dependant on appropriate information and communication technology, which many Trusts may lack; it does not facilitate non-GP referring professionals and does not allow for Consultants to prioritise according to clinical need. Furthermore it requires an agreement between the GP and Consultant about what is an appropriate referral but primarily leaves the gate open for GP's to make referrals 'as they see fit', which may not, under the previous system, have been accepted by a Consultant for his/her speciality. This problem in itself has the potential to 'break the system' in view of research discussed earlier on the internal dynamics that affect and control GP referring patterns (Hamblin et al., 1998). It is difficult to envisage how the process of GP's recognising more people with the same degree of need and Consultants' consequential thresholds will be managed.

The Audit Commission (2003) Outpatient Review of National Findings stated that waiting times are being reduced by increasing the number of patients seen. Referring



to the earlier part of the present review the Audit Commissions' statement is suggestive of the NHS Improvement Plan being a 'mass waiting list initiative' where all efforts are concentrated on increased activity in the belief that this will reduce waiting times and therefore lead to a better NHS and increased patient satisfaction. Historical and international evidence have shown that increases in activity to reduce waiting lists have resulted in increased referral rates (Hamblin et al., 1998). Open access to the booking system removes the 'gatekeeper' for GP's and therefore maintains the equilibrium, resulting in waiting times eventually reaching the previous level or higher (Frost, 1980). This may account for the increase in the number of patients waiting in 2004 as opposed to 2003 (DoH: 2003/0311; DoH, 2005). Individual departments who have introduced the booking system reported improved waiting times and DNA rates (Lloyd et al., 2003; NHS Modernisation Agency, 2003), however the Audit Commission (2003) found no difference when comparing the performance of Trusts who had fully implemented the booking system and those that had not.

### **Demand and Capacity**

Despite the fact that waiting times for a first outpatient appointment appear not to be on target as demanded by the NHS Plan the statistics highlighted above show a marked reduction in comparison to previous statistics. The Audit Commission (2003) researched the demand faced in the form of referrals to Consultants and found that in general surgery, the median number of referrals for each whole time equivalent Consultant with the speciality was just over 1000 per annum, however the range was between 500 and 2,600 (Audit Commission Survey, 2002). Given the variation in referral rates, it is surprising that there was no significant association between the departments with higher referral rates per Consultant and long waiting times (Audit

Commission Survey, 2002). The absence of association indicates that Trusts may be accommodating the number of referrals received.

An outpatient survey 2004/2005 found that 80% of patients waited less than 3 months for a first outpatient appointment compared to 75% reported in the outpatient survey 2003 (Healthcare Commission Patient Survey Programme 2004/2005). The survey suggested movement in the right direction to meet waiting times targets outlined in the NHS plan, which states a maximum wait of three months by the end of 2005.

However, it is important to consider that the figures cited in the survey are based on an overall response rate of 59% (84,280 respondents out of a total of 143,596) which is not a true representation of the population.

### **Quantity versus Quality – Service User Perspective**

The outpatient survey 2004/2005 found that while fewer patients were waiting over 3 months for their first appointment the quality of their care was being compromised, suggesting there may be a correlation between higher quantity and less quality. In relation to patient choice the survey found that 70% of patients were not given a choice of appointment date and time, which does not fulfil the expectations of the NHS Improvement plan in relation to partial or full booking systems. From this 20% of appointments were changed with later appointments given without explanation. This was a slight improvement from 2003 where 23% of appointments were changed.

Between 2003 and 2004/2005 the number of patients who saw a Doctor during their outpatient appointment decreased with 82% of patients seeing a Doctor at some point in their appointments compared to 84% in 2003. Of these 51% spent less than 10 minutes

in consultation with the Doctor and 10% less than five minutes which was the same reported in 2003. This invokes the question as to what quality of care and understanding can be obtained and given within this amount of time. Is this the strategy for how Doctors are seeing more patients and hence reducing waiting times? Furthermore, just over half of the patients (55%) in both surveys saw a member of staff other than a Doctor in their outpatient appointment. In follow up appointments 65% of patients did not see the same Doctor or member of staff in their follow up appointments (2004/2005 survey with no comparative data in 2003 survey).

The 2004/2005 survey asked the question 'How Would You Rate Your Health in the Past Four Weeks'. In response to this question 88% reported their health to be 'fair to excellent'. The survey indicates that each Trust identified 850 patients who had attended their outpatient department in June, July or August 2004 and aged over 16. There is no indication as to whether the patients were discharged or in a process of continuing care and so it may be assumed that both are incorporated. This being the case the significance of 88% reporting fair to excellent health is confusing. Is the question purporting that the given treatment had been successful and therefore lending argument to the quality of care, or is it indicative of the patients' measure of health and therefore questionable whether the appointment is at all necessary. Further investigation would in itself give insight into the actual need for an appointment, level of need, whether all referrals are appropriate and consequently reducing the waiting list at source.

### **Quantity versus Quality - Media Reports on Patient Experiences**

A considerable level of publicity has been produced through the media over the last few years criticising the reported figures and highlighting how quality has been compromised for the sake of quantity across all aspects of the NHS in a bid to reduce waiting times.

In 2001 the Guardian newspaper reported the allegation from health watchdogs of the Government conceding waiting times in Hospital Emergency Departments. They argued the NHS will only improve if the real experience of patients improves and not just the management figures that tell only half a story. Ms. Manero from the Health Watchdog stated they are not saying that the Department of Health is deliberately distorting the figures, but rather they are nervous to change from a system devised in 1995 to a system that would show the true wait (Carvel, 2001).

In 2003 the NHS chief executive Sir Nigel Crisp claimed, in the Guardian newspaper, that waiting times for operations were going down and the fall was accelerating. However the journalist Tash Shifrin argued that the way key target areas are measured had been changed again, in a repeat of the statistical manoeuvring featured in the NHS Chief Executive's May 2003 annual report. In May 2003 reported figures sparked controversy as they had been measured in just one week at the end of March (Shifrin, 2003).

For the quarter period April to June 2003 the report claimed 90% of patients were seen at Accident and Emergency departments within the four-hour target, however unlike

the previous quarter, reporting patients seen at minor units and High Street walk in centres were also incorporated in the same statistics. This increased the percentage of patients recorded as seen within the target time as the shorter waits at minor injury units balanced out poorer Accident and Emergency figures (Shifrin, 2003). Health Secretary John Reid defended the figures by arguing they were comparable because minor injuries that might previously have been seen at Accident and Emergency were seen sooner in new minor injury units (Shifrin, 2003).

In May 2004, a further article in the Guardian reported by Tash Shifrin, cited Nigel Crisp claiming in his current annual report a continued fall in waiting times. He apportioned this to a move towards treating more patients in the community and outpatient departments. He was resolute that by speeding patient care, the quality of care was also improving. Shifrin argued the report echoed its predecessors by portraying data selectively. The Accident and Emergency target then set for 90% of patients to be seen within four-hours still included statistics from minor injury clinics and walk in centres. According to Shifrin, the annual report showed figures at just over target at 91% for October to December 2003, while it cited validated management information for March 2004 as 93.7% rather than the whole three month period.

Shifrin found that Department of Health data not shown in Nigel Crisp's report put the figure for waiting times in major Accident and Emergency departments below the target 88.3% between October and December 2003, which were the last quarterly available statistics prior to the annual report year end April 2004 (Shifrin, 2004).

In December 2004, Sky News reported that hospital waiting lists had reduced by a third in the last six years according to the NHS annual review. However, during this report Nigel Crisp conceded that more work was needed to improve the NHS as a whole and cut waiting times further. Crisp also pledged to tackle the so called 'hidden' waits so that waiting times took into account 'the whole patient journey' (Sky News, 2004).

Tony Blair, Labour Prime Minister, pledged to cut waiting times for hospital treatment to a maximum of 18 weeks (Sky News, 8<sup>th</sup> March 2005). He vowed to change the way waiting times are measured to ensure the 18 week limit is applied from 'GP's door to operating theatre. To help achieve this target Mr Blair proposed an increase in NHS capacity by recruiting more Doctors and nurses and contracting 250,000 additional operations to the private sector. Mr Blair stated his intention to ensure all patients will be given unlimited choice over which hospital treats them by 2008.

In both Sky News reports the necessity to record 'real' waiting times in official reports was acknowledged. This suggests recognition at some level that data previously detailed is flawed, confounding and therefore inaccurate. This is not to say waiting times are not moving in the right direction but what is disputable is the pace of change and the quality of care which results.

Jennifer Dixon from the health charity King's Fund purported on BBC News (18<sup>th</sup> March 2005) that hospitals are under pressure to get waiting times down. Dixon argued that part of the problem is a bottleneck in capacity. In the same news report a hospital was reported to be using a mobile surgical unit based in a car park for carrying out up to 70 operations a week. The unit was described as a conventional operating room,

based in temporary accommodation which can be dismantled and moved when needed. The aim of the building is to reduce pressure on waiting times and to eventually be adopted by other hospitals. The report stated that by the end of 2005, the present hospital hopes to perform more than 100 operations a week in the unit (Dixon, 2005 BBC News, 18<sup>th</sup> March).

In a corresponding news report (Oakeshott & Beattie: Evening Standard, 18<sup>th</sup> March 2005) the same mobile theatre was criticised for compromising patient care. The unit is used against the advice of senior surgical staff who believe it carries a significant risk for the welfare of the patient because there are no intensive care facilities or emergency blood supplies on site. Critics at the hospital claim the unit is being used to meet waiting time targets on the Accident and Emergency ward by freeing beds. Dr Storrington claimed patients are being moved around the hospital and junior Doctors are tearful and totally exhausted. He described the management of patients at the best of times as inadequate and now hopelessly overstretched as a consequence of following political dictates.

Oakeshott & Beattie (The Evening Standard, 2005) revealed that London hospitals are facing a £100 million hole in their finances, which has resulted in the closure of wards and operating theatres, and a reduction in staff. They further reported that sick children are being turned away, whilst another London hospital is cutting its staff by 100 and closing beds due to £20 million debts. In the report Health Secretary John Reid insisted these are isolated examples arguing that healthcare in London is improving significantly. Reid affirmed his statement by stating waiting lists for outpatient appointments are at their lowest for 17 years and are expected to fall further in 2006

(Evening Standard, 2005). Given the recognition of 'hidden waiting times' and 'real waiting times' that are not yet incorporated in present data, the question arises as to whether existing statistics can be upheld over the experiences of Doctors and nurses and indeed patients.

In a paradoxical transfer of power due to a positive performance in relation to managing waiting times, a Leeds hospital was precluded from managing their own waiting lists due to patients being seen too quickly (Shaw, Leeds Today Evening Post, March 2005). The Leeds North West Primary Care Trust who pays for the healthcare decided to take control over whom and when patients are seen due to the Leeds hospital seeing patients as speedily as possible, therefore in some cases performing months ahead of target waiting times. Consequently, local health care commissioners found themselves over budget due to the cost of more operations than they had anticipated. The Primary Care Trust in a bid to 'balance the books' procured control to impose their management. Inevitably patients who could have been seen sooner now face longer waits.

A local Councillor expressed his view that the issue depicted what inadequate finance and a target culture is doing to the service patients receive. He argued it is a sad indication of the state of the health service when Doctors are told they must do operations to fit with budget targets as opposed to medical reasons, and operations are pushed back to meet such targets. He highlighted the biggest issue in the health service today: that Doctors and nurses are not given the freedom to make clinical decisions in the best interest of patient care, and concluded it was time that medical professionals, not managers or politicians decide what is best for the patient (Greg Mulholland cited



by Shaw Leeds Today Evening Post, March 2005). In a statement of defence a spokesman disputed the claims stating that Trusts have a statutory duty to achieve financial balance. He justified that the level of activity carried out by the hospital had been greater than they were contracted to do, which resulted in additional financial implications. The spokesman clarified the Primary Care Trust's intention to hold its own waiting lists of patients with the intention being to present the hospital with a list of patients to be seen each quarter. In addition to this they stated that routine cases which didn't need to be seen would be kept on file (Shaw, 2005 Leeds Today Evening Post).

### **Evaluation of Present Day Reforms**

The philosophical thinking and values behind the NHS Plan (2000) have ostensibly been shaped by the service users' perspective of how they wanted the NHS to function. One of the main factors of the Plan was to reduce waiting times without compromising the quality of care. The literature cited suggests that although changes have taken place this has not, and will not, be achieved. One of the contributory factors must be the inaccurate and selective reporting of data. Waiting lists are substantially longer than declared by the Department of Health (Radical Statistics Group, 1995; Pope, 1991; Armstrong, 2000), according to published figures almost 50% of referrals, which are not GP referrals, are not included in the published statistics (Department of Health, 2005). Consequently, services are endeavouring to meet a demand which is double that for which they are given recognition or funding. This has potential to affect strategic service planning and development at a higher level with the impact transferred and experienced at ground service level. With such penalties imposed (Hemingway &

Jacobson, 1995; Hughes & Griffiths, 1999; Department of Health, 1998; Directgov, 2000) services have no alternative but to increase capacity. However, according to reports the increase in capacity is to the cost of a decrease in the quality of care (The Audit Commission, 2003; Carvel, 2001; Shifrin, 2004; Sky News, 2004; BBC News, 2005).

The NHS Plan (2000) acknowledged that systems put into place to reduce waiting times such as the full booking systems will only achieve success if GP referrals do not increase. However there does not appear to be any suggestion of management to prevent this happening, which according to Hamblin et al. (1998) is inevitable. Arguably, all recent attempts at Government, strategic and service levels to reduce waiting times have inevitably resulted in increased referrals. Therefore the changes that have occurred and discussed throughout this review have been variations of previous 'waiting list initiatives'. According to Hamblin et al. (1998) the idea of reducing waiting times through increased activity is based on misconceptions of underperformed work rather than the measurement of part of a dynamic system at a point in time. Hamblin et al. (1998) insisted that failure to understand the intrinsic workings of the system will inevitably result in longer waiting lists as opposed to successfully reducing waiting times.

The Department of Health (1998:98/190) when proposing a whole system approach to reduce waiting times considered the inclusion of family Doctors, primary care services, community health and social services and mental health services. Although a move in the right direction, the Department of Health's systemic thinking was one of exclusion

rather than inclusion using a top down approach without consideration of 'low level' intricate systems.

### **Academic Research – The Answer?**

Pope (1991) argued that the succession of short term interventions aimed unsuccessfully to reduce waiting lists seem to be an account used to justify the policy it produces. They are developed in response to political pressure and a desire by ministers and health service managers to 'be seen to do something' about the waiting lists problem. Pope purported that considerable energy is exerted in developing explanations about why waiting lists have become a problem, and she classified the findings into individual theories and system theories. Pope's description of these theories duplicates the researched findings already highlighted but provides a framework in which to place each argument for clarity.

Individual theories hold patients, Doctors and managers responsible for the waiting lists problem. Patients 'mess up the queue' by not attending, cancelling admissions at short notice, holding a place in case they get worse, or registering at two or more hospitals (Houghton, 1989; Frankel, 1989). GP's are accused of inappropriate and over referring (Jessop, 1989); Consultants are accused of inducing demand by their presence and keeping long lists to attract resources or private patients (Roland, 1988; Todd, 1984; BATTERY, 1979; Frost, 1980). System theories provide systematic explanations: waiting lists are the consequence of the Governments' inability to pay (Cooper, 1975). Under funding is blamed and waiting list figures are quoted to illustrate the inadequacy of spending in health care. Financial restraints limit the number of Doctors and hospital

capacity (Cooper, 1975) and introduce market mechanisms for the private sector (Culyer, 1976; Cullis, 1983).

Pope (1991) argued that both individual and system theories take the position that there is a rational queuing system that isn't working, either because people are misbehaving or the system is malfunctioning. Frankel (1989) characterised the waiting list as a pool of unmet need and likened it to a mort lake. As discussed earlier Frankel identified certain referred conditions that were of little interest to either public response or professional priority. He stated:

*“We are not dealing with a simple queue where the flow of demand is dammed back by banks that are too narrow. The formation of waiting lists corresponds more with the development of an ox-bow lake. The meandering flow succeeds in taking a short cut, and so leaves an isolated lake. The alternative term for an ox-bow lake, mort lake, offers a more graphic metaphor for the pool of demand that is set to one side in this way.”* (Frankel, 1989: p. 57)

Pope (1991) disputed that the queuing system rationale and mort lake theories yielded the full picture, arguing that they fail to uncover the mechanics of a waiting list. From a sociological perspective, Pope studied the 'low level bureaucrats' in the medical setting, which had previously been neglected. Pope concluded that waiting lists are the base of the organisation where the supplier meets the customer. Pope found that they are overseen by higher level management who produce statistical information, they remain the property of individual Consultants but they are collectively maintained by the admissions staff that she identified as street-level managers of the waiting list.

Admissions staff have contact with medical staff, managers and patients but do not belong to any group. This positions them between the patient and hospital.

Pope identified situations where clinicians worked the system, for example blocking beds by patients who were fit for discharge that are conveniently vacated when a waiting list patient fits the Consultant's 'signature'. The term 'signature' was coined by Wennberg (1982) and denoted a Consultant's preferred work or operation procedures he/she is free to determine. Pope noted that the admission staff were aware of these practices but turned a blind eye.

The admission staff have considerable power to use their discretion when selecting patients for admission. Pope detected a negative and positive criterion that was used when admission staff were designating a 'privileged member of the queue'. Negative criteria applied to difficult patients i.e. patients who are not on the phone or have been on the waiting list a long time and therefore difficult to contact. Positive criteria applied to patients who are readily contactable and/or have recently attended hospital. Further to this 'being in the right place at the right time' has a part to play. Pope witnessed an example when a few minutes after receiving a cancellation call; a patient rang to enquire about his position on the waiting list only to be given the recent cancelled slot.

In concluding her research Pope argued that the queue (Doran, 1990) and mort lake theories (Frankel, 1989) offer some insight into how waiting lists are managed but suggest a fixed and passive presentation, which fail to understand what waiting lists are

and how they work. Pope proposed that the waiting list is better understood as a 'store' and those working within it as 'storekeepers':

*"It is only by considering the context of waiting lists and examining how they are created and recreated by individuals will we begin to understand the phenomenon. The metaphor of the 'store' goes some way towards describing some of the processes involved in waiting lists and perhaps more accurately captures the variety of interaction they encompass."* (Pope, 1991: p. 210)

Pope's research highlights a fundamental and crucial critique of the waiting list phenomenon. The insights go further than describe the dynamics of a waiting list and offer an intricate systemic explanation that goes beyond the periphery of the problem. The findings could have been decisive and pivotal if taken and operationalised by the 1997 commissioned 'Regional Waiting List Task Forces' and the 'National Waiting List Action Team. However the research was a qualitative case study centred on a District Health Authority on the suburban fringe of a town. The findings were an analysis of qualitative data recorded in near verbatim notes following interview or observation periods. The choice of data collection and analysis yielded a significant understanding, high in reliability of the problem for the District Health Authority involved. It puts into question the validity and therefore the ability to generalise across Health Authorities. Given the important observations and conclusions raised, further research is needed across areas to quantify the extent and depths of the issues highlighted for strategic change to happen.

## **Waiting Times – the Future?**

The last ten years have seen many changes in waiting list management in a bid to reduce waiting times and maintain quality. Although not on target, statistics show that waiting times are decreasing (Department of Health, 2005) but to the detriment of quality of care (Healthcare Commission Patient Survey Programme, 2004/5).

Accuracy and honesty is needed when reporting figures so that genuine planning can take place incorporating all systemic levels. The constant ‘moving’ and ‘shifting’ of power and responsibility suggests that there is no real understanding of the phenomenon or resolution (Newton et al., 1995; Doran, 1990; Hemingway & Jacobson, 1995; Hamblin et al., 1998; Hughes & Griffiths, 1999). Shifting power to the patients albeit ‘service user friendly’ will only serve to add to the problem if service users do not have adequate information or understanding to make informed decisions. It seems from the changes that have occurred academic research has not been considered to inform strategic changes. Research has established good insight into the waiting list phenomenon and needs to continue to inform dynamic change (Frost, 1980; Frankel, 1989; Pope, 1991; Hamblin et al., 1998; Foreman & Hanna, 2000; Pope & Sykes, 2003). In relation to service engagement, prominence should not be with figures and statistics to decide good practice. Engagement and patient-practitioner therapeutic relationship are essential for effective outcome. Negative feelings from the patient due to managing the referred problems alone whilst waiting may effect the initial engagement. In terms of counselling/psychotherapy the first meeting is crucial (Rogers, 1951; Woolfe, 1990). In terms of physical intervention trust with the professional is essential. Therefore experiences of waiting need to be researched as well as existing surveys into experiences once the patient has engaged.

Psychological research has an important role amid the political agenda that would be wise to consider researched findings. Research into the waiting list phenomenon given the ongoing changes over the last ten years needs to be undertaken and commissioned for psychological research, especially in view of the implications to psychological practice. If the NHS Plan (2000) is to continue the line of placing service users at the centre, research conducted by counselling psychologist, given their humanistic and existential-phenomenological philosophy and experimental behavioural scientific roots (Strawbridge & Woolfe, 2003), is in a good place to inform the Department of Health in its policy making.

### **Introduction to Research Paper**

Whilst researching waiting lists within CAMHS, Rawlinson & Williams (2000) were surprised to find no recent papers which specifically address the issue, despite CAMHS being high on the political agenda in terms of a need to increase service provision and reduce waiting times. In an attempt to address some of these issues, the NHS Health Advisory Service (1995) published a thematic review of Child and Adolescent Mental Health Services 'Together We Stand', which proposed a four-tier model for commissioning and delivering comprehensive services. Four years later, in an audit report of specialist mental health services for children and young people (Children in Mind), the Audit Commission took the four-tier approach as its baseline and confirmed its applicability to the future planning of mental health services for children. The four-tier strategic framework is now widely accepted as the basis for planning, commissioning and delivering services. Although there is some variation in the way the framework has been developed and applied across the country, it has created a common



language for describing and commissioning services. A description of the tier framework is as follows:

- Tier 1

CAMHS at this level are provided by practitioners who are not mental health specialists working in universal services; this includes GPs, health visitors, school nurses, teachers, social workers, youth justice workers, voluntary agencies.

Practitioners will be able to offer general advice and treatment for less severe problems, contribute towards mental health promotion, identify problems early in their development, and refer to more specialist services.

- Tier 2

Practitioners at this level tend to be CAMHS specialists working in community and primary care settings in a uni-disciplinary way (although many will also work as part of Tier 3 services).

For example, this can include primary mental health workers, psychologists and counsellors working in GP practices, paediatric clinics, schools and youth services.

Practitioners offer consultation to families and other practitioners, outreach to identify severe or complex needs which require more specialist interventions, assessment (which may lead to treatment at a different tier), and training to practitioners at Tier 1.

- Tier 3

This is usually a multi-disciplinary team or service working in a community mental

health clinic or child psychiatry outpatient service, providing a specialised service for children and young people with more severe, complex and persistent disorders.

Team members are likely to include child and adolescent psychiatrists, social workers, clinical psychologists, community psychiatric nurses, child psychotherapists, occupational therapists, art, music and drama therapists.

- Tier 4

These are essential tertiary level services for children and young people with the most serious problems, such as day units, highly specialised outpatient teams and in-patient units. These can include secure forensic adolescent units, eating disorders units, specialist neuro-psychiatric teams, and other specialist teams (for children who have been sexually abused, for example), usually serving more than one district or region.

Despite the framework and additional funding waiting lists in CAMHS, like other NHS departments, have continued to grow (Stallard & Potter, 1999). Rawlinson & Williams (2000) found a correlation between non-attendance and long waiting times. They purported that the longer a family have to wait for an appointment the less likely they are to attend resulting in unfulfilled appointments and failure to efficiently use clinician's time. Existing research has taken a hypothetical-deductive approach to understand why families do not attend in a bid to address the waiting list issue. Conversely the objective of the present research is to gain a rich understanding of the waiting list experience from service users. Like Pope (1991) the aim of the research is to go beyond the periphery of the problem to elicit a greater understanding that can

inform substantial service changes as opposed to 'token gestures' that make no real difference to the 'status quo'.

## **RESEARCH PAPER**

# **An Investigation into the Waiting List Experience – Exploring Parents Views of Children Referred to a Child and Adolescent Mental Health Service.**

## INTRODUCTION

Waiting lists have been viewed by various Governments as a backlog of untreated patients who could be removed by a short-term burst of activity (Hamblin, Harrison and Boyle, 1998). However Hamblin et al (1998) suggest waiting lists continue to grow even during periods of waiting-time initiatives.

In relation to Child and Adolescent Mental Health, the National Health Service Advisory Service (1995) estimated that at any one time 20% of children present with a diagnosable mental health disorder. The profile of Child and Adolescent Mental Health Services (CAMHS) has been placed increasingly higher on the agenda of commissioning authorities and service providers, yet despite this Rawlinson and Williams (2000) concluded from a published Audit Commission of Child and Adolescent Mental Health Services within England and Wales, that 10% of NHS Trusts could not offer an initial appointment for non-urgent cases within 6 months.

In a bid to improve CAMHS, the NHS Advisory Service (1995) introduced a four tier framework (see Appendix I) and allocated additional NHS funding. The framework identified the different levels of service delivery, however it did not provide purchasing authorities with clear ideas how it could be operationalised within existing resources. For example, the framework described when working within (CAMHS) that one referral demanding tier 3 interventions needed two or more clinicians to work with various members of the child's/adolescents family to ensure change. Stallard and Potter (1999) in their study found that one in five referrals were estimated to require specialist tier 2 and 3 interventions. The need for more than one clinician working with a referral/family is not taken into consideration when measuring the performance of a

service by the numbers of active referrals and the length of its waiting list. Even tier 1 and tier 2 interventions can demand more than one therapist if the case demands a child worker and a separate parent worker.

Despite the framework and additional funding, Stallard & Potter (1999) argued that CAMHS remain in crisis. Lengthening waiting lists and demoralised clinicians, lead to increasingly narrow prioritisation of referrals and raise concerns about inaccessible and unresponsive services. With further funding now limited and waiting times still increasing, Rawlinson & Williams (2000) stated, commissioning authorities and service managers have turned to examining whether existing resources are appropriately targeted and being used effectively.

### **Non-attendance – the Cause?**

Rawlinson & Williams (2000) found that almost one in five families did not attend their initial assessment appointment. They found strong evidence that poor attendance rates are closely associated with longer waiting lists and proposed a model suggesting that clients who have waited excessively are less likely to attend and the increase in ‘did not attend’ (DNA) rates therefore results in an unfulfilled appointment and unproductive time of clinicians’ resulting in the non-reduction of the waiting list (see Appendix II). This could be suggested that ironically long waiting lists perpetuate long waiting lists.

### **Non Attendance – the Reason?**

If non-attendance of initial assessment appointments is a major contribution to the maintenance of high waiting lists; steps are needed to discover other reasons why clients choose not to attend. Lefebvre et al (1983) researching in Canada considered whether DNA rates related to clinical procedures such as referral and screening patterns or whether they are pre-determined by particular patient characteristics?' They surveyed the 13.6% (40 clients) of their clinical population that they called the 'no-show group' and compiled a demographic profile for each of them recording age, gender, geographic distribution and socio-economic status. They found a slightly higher proportion of girls in the 'no-show' group and found that those most likely to DNA were in pre-school or adolescent age groups. Higher percentages lived out of the city and were more likely to be from a lower socio-economic class. However, they found that out of the 40 no-show clients, 22 reported the long period of time waiting to be the major contributor to them choosing not to attend. Lefebvre et al (1983) stated that although some have argued that waiting lists have a therapeutic value in screening out unmotivated patients/clients, their findings suggest that lower socio-economic families are more likely to not attend weakened this rationale as they are most at risk for multiple problems and emotional disorders (Staver & LaForge, 1975; Griffin, 1963; Raynes & Warren, 1971).

Stern & Brown (1994) examined the effect on waiting lists and attendance in an English study of appointments in the Child and Family Clinic at the Tavistock Centre, London and Child and Family Clinic in Watford. They found similar results namely a significant positive relationship between non-attendance of first appointments with

length of waiting lists, and no correlation between non-attendances and other parameters such as age, gender, referral source, and nature of presenting problem, family structure and previous contact with the clinic. They argued that the consequence of long waiting times result in only a minority of children with disorders being reached by the service. This may have implications for the mental health of the children in the area served by the clinic. Stern & Brown call for these implications to be considered for future service development planning and request that further research be conducted to address the

*“mismatch between resources in child and family psychiatry and the need for services” (p 228).*

Following Stern & Brown (1994), Stallard & Potter (1999) found that the same issues were still a major problem five years later. They stated that the need for Child and Adolescent Mental Health Services was potentially as high as ever and estimated that at any one time as many as 20% of children present to Child and Adolescent Mental Health Services with a diagnosable mental health disorder. Similarly to Stern & Brown (1994), they suggest that only 9% of the children are referred to a specialist Child and Adolescent Mental Health Service and the actual number of children seen is even lower than this ‘conservative’ estimate (Kurtz, 1996). They argue that even with this smaller percentage of actual need, the capacity of the services to effectively respond is severely challenged.



### **Non-attendance – The Way Forward?**

With high demands, lack of resources and limited future funding it could be suggested as Rawlinson & Williams (2000) argue that there is a need to examine how existing resources and policies could be used more effectively. In respect of the above research, it may be that if non-attendance rates could be improved, the waiting lists would decrease. The effect of improved attendance rates would result in more efficient use of therapists' time and resources, and more importantly children and adolescents with mental health needs and their families will be seen sooner. If the length of waiting time is the highest predictor for non-attendance then it follows that shorter waiting time for a first appointment should improve attendance rates.

Robin (1976) in adult psychiatry found evidence that immediate appointments resulted in significantly higher attendance rates. Jaffa & Griffin (1990) conducted research in child psychiatry and found similar results. However, they identified a two-week threshold and found if appointments were given within two weeks there was a significant higher attendance rate whereas appointments offered after the first two weeks were more likely to be unattended. They found the difference to be statistically significant,  $z = 2.14$ ,  $p < 0.05$  and suggested possible explanations: an early appointment might be an intervention when the family is in crisis and therefore more open to influence. If an appointment is delayed, the family is more likely to establish new behaviour patterns and become less open to outside influences and a reduced willingness to attend their appointment. Although Jaffa & Griffin (1990) were unable to surmise from their research why the two week cut off should be so significant, they suggested it might be related to the mean time for crises to generate, peak and resolve, and the point at which outside help is sought. They recognised that in some cases the

presenting problem might be mild and transient and a delayed appointment would be appropriate to allow the problem to resolve itself without specialist help, however, when the presenting problem is more serious, delayed help might make the family feel that the crisis has settled when in fact they may have settled into a new, and not necessarily healthily, pattern of functioning. A delay in an offer of an appointment may therefore also mean an opportunity for effective intervention has been lost or at best, longer and more complex intervention will be necessary. Plante & Meloche (1977) found by discontinuing their waiting list and seeing all referrals promptly, the initial contact made it easier to allocate resources more effectively and make suitable management plans. They found that 15 – 20% of cases actually required no further intervention, as one face to face contact in which advice was given was sufficient.

### **Conclusion**

A number of studies have indicated that high non-attendance rates are associated with the length of waiting lists. Rawlinson & Williams (2000) stated:

*“In view of the length and increasing use of waiting lists in many services that was noted by the audit commission and the problems in clinical practice that they represent, it might be considered surprising that there are no recent papers that directly address the specifics of this issue” (p. 6).*

The present literature search supports Rawlinson & Williams statement above given that most of the research found is dated or conducted internationally. What was more surprising was that even though the research cited spans almost twenty years, the same is reported with no change. It seems that emphasis has been placed on high waiting

lists, blaming lack of funding, under staffing and mis-management and even when attempts have failed to address these, such as waiting list initiatives, nothing has changed (Hamblin et al, 1998).

### **The Present Inquiry**

The research was based in a Child and Family Service, part of Child and Adolescent Mental Health, serving a socially deprived population. Currently there is an 89 week waiting list for non-urgent cases. The non-attendance rate for initial appointments is currently 27% with just over one in four clients not attending initial assessment appointments. Clinicians routinely book between one to two hours for each assessment. The referral process utilises a post card opt in system and therefore the waiting lists consists only of families who have indicated their willingness to engage, yet the non-attendance rate remains high. It may be contended that if waiting times can be improved by reducing non-attendance, then services have a professional and ethical responsibility to investigate how this can be achieved. Existing research has attempted to understand why families do not attend by examining client characteristics, demographic information and socio-economical factors (Lefebvre et al., 1983; Stern & Brown, 1994; Stallard & Potter, 1999). However these studies have looked at researchers' hypothesis of causes related to the client/family from a hypothetico-deductive stance. It has also been agreed by Pope (1991) that research to date on waiting lists and waiting times has been dominated by political and medical perspectives and therefore crucial questions are left unanswered. There appears to be no research to date that has considered asking families about their experiences of waiting to gain a phenomenological understanding and generate a theory grounded from data as opposed to being imposed upon it. This is surprising given the present principles of service-user involvement advocated by the Government, encouraged by

strategic and service commissioners and central to the NHS Plan (2000). If any change is to be effective the service-users voice and right to have an opinion in the planning of services that may affect their lives is essential (Holosko, 2001).

May (2001) stated that any 'decent' society that wishes to be fair would seek out service-users views and welcome their contributions for their difference and uniqueness. He argued that psychologists need to be prepared to make changes in the practising of mental health based on the service users view whether they felt the view was right or wrong. Holosko (2001) pointed out that unless service-users are taken seriously at all levels within mental health organisations, changes on top will not be changes that alter anything. The present research is conducted within an ethos which views service-user participants as valuable contributors that can provide insight toward a positive change.

The objective of the present inquiry was to gain a rich understanding of the waiting list experience from the service users' perspective without previous researcher bias. The service user as referred to for the purpose of the inquiry was the parent(s) of the child/young person referred to the Child and Adolescent Mental Health Service.

The justification for the inquiry from the researcher's point of view as a counselling psychologist was two fold. Firstly the motivation was borne from a desire to develop the service so that children, young people and their families experiencing mental health difficulties may be encouraged to attend and in doing so reduce the non-attendance rate to eventually reduce the waiting list and waiting times. Achieving this would increase the capacity of the service and consequently lead to broadening the referral criteria for acceptance of referrals for children and young people who presently have a mental

health difficulty and would not previously have been referred as found by Stern & Brown (1994) and Stallard & Potter (1999).

Secondly, as a counselling psychologist in training the researcher has experienced negative beginnings with families due to their long waiting experience. Initial sessions have been tense until the experiences have been worked through. It is important to promote attendance to the Child and Adolescent Mental Health Service but equally it is important to have a positive beginning to encourage a therapeutic engagement crucial for therapeutic change (Rogers, 1951; Mearns & Thorne, 2001; McLeod, 2003). It is anticipated that by gaining an understanding of the waiting process from the service user intervention can be improved to promote a positive beginning. A positive initial therapeutic engagement may reduce the length of therapy required and as a consequence serve to increase capacity and subsequently also reduce waiting times.

## METHOD

### **Rationale and Aims for the Study**

The literature within the field of enquiry identifies the negative effect of non-attendees on waiting lists (Jaffa & Griffin, 1990; Stallard & Potter, 1999; Rawlinson & Williams, 2000). Poor attendance rates are closely associated with long waiting lists as demonstrated by Rawlinson & Williams; 2000 (see Appendix II). Reasons for non-attendance examined by researchers include information, social class, age and gender (Raynes & Warren, 1971; Carpenter et al., 1981). Waiting list initiatives to reduce waiting times have in some cases worked in the short term, but in most cases have seen an increase in the referral culture (Frankel, 1989; Hamblin, 1998). Past and current referral trends have perpetuated the inconsistency between demand and resources (Jaffa & Griffin, 1990). Understanding the features of non-attendees and attempts to reduce waiting lists has not served as factors to reducing waiting times and therefore encourage attendance.

Research to date has taken a hypothetico-deductive approach, categorising service users on pre-determined dimensions such as age, gender, social group, length of waiting and travelling distance to the clinic (Raynes & Warren, 1971; Staver & LaForge, 1975; Lefebvre et al., 1983; Stern & Brown, 1994; Rawlinson & Williams, 2000). Intentions have been to make service changes in accordance with research findings to improve attendance rates and consequently improve waiting times. Given the current climate of user empowerment and involvement (May, 2001), I was interested in adopting a more exploratory inductive approach to the issue of service-uptake. In particular I wished to

engage with the experiences of parents whose children are on a waiting list at the Child and Family Service, one of the four Child and Adolescent Mental Health teams. I would agree with Holosko (2001) that unless service-users are taken seriously at all levels within mental health organisations, changes on top will not be changes that alter anything. The aim of this research therefore is to gain an in-depth understanding of how parent's experience, and manage, the waiting period with the aim of achieving insight into how their experience may be improved. This would serve to inform future service development in terms of implementing a system to support parent's through the waiting process. Supporting the family through the waiting process may encourage continued interest and consequently attendance, thus meeting the needs of the service user and giving rise to the productive use of the services internal and external resources.

Of equal importance from the standpoint of counselling psychology is an understanding of the waiting experience as a means to promote a positive beginning and encourage a good therapeutic alliance. I have been in situations where parents have expressed anger because of experienced unacceptable waiting times. It is then necessary to work with the negative experiences and feelings before beginning any therapeutic engagement. This in itself increases the number of sessions needed, which subsequently has a direct effect on the waiting list. In terms of engagement, a positive waiting process would assist the beginning of a positive therapeutic alliance between the family and service. The therapeutic alliance is essential for therapeutic change and outcome as it is the mechanism which enables the client to remain and comply with treatment (Bordin, 1979; Sexton & Whiston, 1994). Improving the waiting experience is therefore anticipated to benefit the service, service user and the therapeutic engagement

## **Methodology**

### **Ethical Approval**

This study was approved by the Ethics Committees of Wolverhampton Local Regional Ethics Committee, Wolverhampton Primary Care Trust and the University of Wolverhampton School Of Applied Science (see Appendix IV).

### **Methodological Rationale**

Existing research to improve referral attendance rates has for the most part been embedded in the epistemology of positivism, with the concluding positions being consequences of the researchers' hypothetical standpoints which were tested, quantified, embraced as truth and operationalised. For example, telephone prompting: Burgoyne et al., 1983; Kluger & Karras, 1983, letter prompting: Hochstadt & Trybula, 1980, use of initial questionnaire: Mathai & Markantonakis, 1990; Parker & Froese, 1992, orientation meetings: Wenning & King, 1995, waiting list initiatives: Leff & Bennett, 1998, Jones et al., 2000). However, as Government statistics indicate (Department of Health, 2005), waiting lists continue to be unacceptably high, perpetuate non-attendance and drain clinical resources (Stern & Brown, 1994; Rawlinson & Williams, 2000; Stallard & Potter, 1999). Given that the research was intended to improve attendance to first appointments the question arises as to why service users were not asked for their views as opposed to testing out presupposed hypothesis. Hypothetico-deductive research verifies/tests existing theory and neglects the phase of discovery (Pidgeon & Henwood, 1992). For this reason the present research chose to engage in a qualitative approach adopting a constructivist epistemological position.



## **Qualitative Research**

Qualitative research contributes a body of knowledge about the world, which is different from that generated from quantitative methods of inquiry (Parker, 1998).

Denzin & Lincoln (1994) argued that if phenomenon in the social world is to be understood, researchers need to engage in how the world is perceived through the eyes of the participant and from their own social perspective. The aim of qualitative research is to highlight and elucidate the meaning of social interactions and situations (McLeod, 2003) with the intention of understanding phenomenon rather than explaining it. It is therefore positioned within a broad hermeneutic tradition (Messer et al., 1988).

Qualitative inquiry is embedded within the philosophical position of social constructionism which contends reality is constructed, with alternative definitions of understanding (Gergen, 1985). Fundamental to this is the idea of pluralism, which is defined as 'a philosophical point of view that ultimate reality consists of more than one form of basic substance or principle' (Reber, 1985). Social constructionism purports that all form of knowledge produces images of the world that then operate as if they were true (Gergen, 1985). It argues that all scientific knowledge involves the subjective interpretation of meaning and without this, the hypotheses based on such information is unfounded (Pidgeon & Henwood, 1998). A desire to illuminate and clarify the meaning of social interactions and situations is the qualitative researchers' ethos for selecting participants on the basis of their theoretical significance as opposed to randomised or stratified sampling techniques (Yin, 1994).

Research questions are generally structured by personal and political interests that need to be explored rather than hidden away (Parker, 1992). What has been identified in the present inquiry is a gap in the existing knowledge base about why people do not attend initial appointments. Qualitative research begins by recognising the gap between an object of study, the way we represent it and the way interpretation fills the gap (Parker, 1998). It does not make claim to ultimately fill the gap between objects and representations but works with the problem as an interpretative undertaking. This was the ethos behind exploring parents' experiences on the waiting list as a way of understanding non attendance as opposed to asking why they choose not to attend. McLeod (2003) argued that giving the client 'a voice' allows their experiences and life stories to be documented and is therefore invaluable to the smooth and efficient running of services and agencies.

Qualitative research is not a unified activity (Strauss & Corbin, 1998) thus there is no single correct qualitative method (Parker, 1998). However the aims of the present research were to gain a rich understanding of parents' experiences in order to inform service development and encourage a positive therapeutic engagement. Restricting the findings to description alone would not go far enough in meeting the aims. A decision was therefore made to engage in a qualitative approach informed by Pigeon & Henwood's version of grounded theory (1992). These principles would allow coding and interpretation to be used as an analytical tool leading to development of central themes and provide a model of understanding of parents experience's whilst waiting for their child's initial appointment. This process of research involves the collection of detailed descriptive material from appropriate informants, coding, categorising and interpreting the subsequent data (McLeod, 2003).

## **Grounded Theory**

Within grounded theory the task is to discover new ways of making sense of social phenomenon, generate a formal framework (theory) for understanding the phenomenon and ensure the theory is grounded in the data rather than being imposed upon it (McLeod, 2001). Pidgeon & Henwood (1998) recognised that grounded theory resonates to the features of qualitative research in its commitment to exploring meanings in their full complexity and context from the participants' constructions of their world. However, confounding this position, they also recognised that grounded theory as originally conceived (Glaser & Strauss, 1967; Strauss & Corbin, 1990) rests squarely upon a positivist epistemology. This recognition was founded by the underlying principles of Glaser & Strauss (1967) that theory is discovered by data (Observation→Theory Relationship). This implies that a set of social or psychological relationships can exist objectively in the world, can be reflected in qualitative data and can be 'captured by any researcher'.

As a resolution to the paradox, Pidgeon & Henwood (1998) argued that it makes no sense to claim that research can proceed from testing theory alone or from a pure, inductive analysis of data. Within grounded theory what appears to be emergence of theory in reality is the result of a constant interplay between the data and the researcher's developing conceptualisations between ideas and research experience (Bulmer, 1979). Henwood & Pidgeon (1992) identified a number of interrelated features that shape the interplay and mark the differences between grounded theory and the hypothetico-deductive method. These include the assumption that the relationship between theory and data will at first be ill defined; acceptance of the need to be tolerant of, seek out and explore ambiguity and uncertainty in this relationship when

constructing a category system that is both relevant to the problem and fits the data; and the exhortation to researchers to avoid premature closing or fixing of theory whenever new insights might arise (Henwood & Pidgeon, 1992:104).

Taking this position, the idea of theory generation brings into prominence the active and constitutive analytical process of inserting new discourses within old systems of meaning, which may be viewed as a constructivist revision of grounded theory (Charmaz, 1990; Pidgeon & Henwood, 1998).

### **The Researcher**

During the course of the study I have been continually employed by the Child and Family Service as well as being a final year Counselling Psychologist in training. Therefore I had a genuine interest in the service development as I would remain in employment post training. Further to this, the humanistic philosophical underpinnings of the counselling psychology training programme, central to my practice, had emphasised the importance of the therapeutic alliance as crucial to any theoretical orientation. Both the desire to improve the service and be effective as a therapist to the referred children, young people and their families was my personal rationale behind the research.

### **Participants**

Participants were the parents of children and adolescents referred to the Child and Family service, this service being one of the four Child and Adolescent Mental Health teams (CAMHS). In qualitative research, participants are selected on the basis of their

theoretical significance rather than in accordance with rules of randomised or stratified sampling (Strauss & Corbin, 1998). The inclusion category for participants was determined by the length of time waiting from receipt of referral for an initial appointment. The threshold of ‘eight weeks waiting’ was selected given the 4 – 6 week critical period that might act as a confounding variable on the data (Jaffa and Griffin, 1990). Exclusion criteria included referrals with a high priority and awaiting imminent allocation, non English speaking parents and referrals that identified children within the ‘Looked after Children’ system.

### **Selection of Participants**

Based on the purposive sampling method (Bowling, 1997), a query was generated on the Child and Family Service database to establish the number of referrals available above the 8 week threshold. The exclusion criteria were applied and remaining referrals were copied on to a separate datasheet. The process for identifying the purposive sample was repeated multiple times, each after a 4 week interval to allow response time. This was necessary as new referrals were received by the Child and Family Service daily, and the number of weeks waiting altered for existing referrals. An example of the purposive samples generated is shown in Table 1. In total 250 referrals were contacted by letter over an eight month period generating 6 participants. Due to time constraints and a lack of response a decision was made to proceed with 6 participants. This yielded a response rate of 2.4%. It is difficult to ascertain why the response rate was so low, although it may be hypothesised that parents did not feel kindly disposed towards the request to participate, given that they remained on the waiting list with no help for the presenting issue.

There did not appear to be any common characteristics between the participants in terms of demographic information or referring problems. Two children had been referred by a paediatrician with a query of autism, the remaining four were referred by their General Practitioners for anxiety, social phobia, complex behaviour problems and obsessive compulsive disorder. Two of the children were involved with other services but were awaiting a diagnosis to which would enable access support from other agencies. In terms of socio-cultural factors, all six parents interviewed appeared to be affluent and possibly middle class. The common denominator that all parents shared were feelings of desperation and frustration at the wait for a needed appointment.

Table 1 Example of Referrals in Purposive Sample following Exclusion Criteria

<i>Number of Referrals</i>	<i>Number of Referrals above 8 Week Threshold</i>	<i>Exclusion High Priority</i>	<i>Exclusion Non-English Speaking</i>	<i>Exclusion Looked After Children</i>	<i>Total of Referrals in Purposive Sample</i>
183	143	11	5	4	<b>123</b>
168	133	5	2	8	<b>118</b>
179	152	13	0	3	<b>136</b>
187	169	6	0	5	<b>158</b>

The number of referrals in the purposive sample generated by the query on each occasion included existing referrals, referrals that had not been included in the previous purposive sample but had reached the eight week threshold and excluded referrals that had been allocated since the last query. Also excluded were the non-responsive referrals that had been contacted previously.

## **Measures**

A semi-structured interview schedule was developed (see Appendix III). The questions chosen to guide the interview were selected following critical reflection on the subject of inquiry synthesised with collaborative discussions within clinical and research supervision. Interviews lasted between 20-45 minutes.

To check the validity of the generated theory a version of respondent validation (Henwood & Pidgeon, 1995) was applied. The theory generated from the collected data was taken back to two of the parents who had taken part in the research whose comments further supported the suggestions for future service development.

To ensure inter-rater reliability, a clinical psychologist and a counselling psychologist from the Child and Family Service were asked to identify examples of the core categories and codes from two sets of transcriptions (Silverman, 2001).

## **Procedure**

An information sheet explaining the nature and rationale of the research, confidentiality issues, anonymity and the right to withdraw was sent to each parent in the form of a letter on letter headed paper (Appendix IV). A reply slip and a self-addressed envelope were enclosed for the parent to indicate their willingness to participate and give permission for telephone contact to arrange an interview appointment (Appendix V). On receipt of the signed reply slip the parent was contacted and an appointment time arranged, to the convenience of the parent, to attend the Child and Family Service for the interview to take place.

At the time of appointment the parent was reminded of the rationale for the research. Confidentiality, anonymity and rights to withdraw were explained. The parent was assured that all audio recordings and consequent transcriptions would be identified by number only and kept in a locked cabinet at the Child and Family Service. The parent was asked to sign a consent form (Appendix VI). The interview was audio recorded and transcribed accordingly. A number was assigned to each transcript. All research material was kept securely within the confidentiality framework of the Child and Family Service.

### **Analytical Strategy**

The raw data provided from transcriptions of the interviews was analysed using principles of Pidgeon and Henwood's version of grounded theory (1992). This form of analysis was chosen because of its interpretivist framework that meaning is not inherent in a reality 'out there' but is constructed by the individual (Segal, 1986). Stratton (1992) stated it is important for qualitative methodology to include a detailed specification of the interview process so that context and meaning are created and understood. With this central to the process, interpretation can decide what conclusion can be drawn from the presence or frequency of aspects produced. These are known as themes and when run concurrent through the majority of transcriptions will give insight into the client's views and feelings. The aim was to move from unstructured data from interviews to a collection of theoretical codes, concepts and interpretations using the principles identified by Pidgeon & Henwood (1992).

Firstly, the data process consisted of gathering rich text through the semi-structured interviews which were transcribed and prepared as individual transcripts with each line



numbered accordingly. To begin the analysis all transcripts were analysed line by line using an open coding process (see Appendix VII) ensuring a full emergence with the data (Pidgeon & Henwood, 1992). Strauss & Corbin (1999) advocate that using the theoretical sampling method when collecting data ensures the greatest theoretical return. However the length of time to gain ethical approval and recruit participants resulted in time constraints. For this reason the comparative method analysis was applied, which is a process of continually sifting and comparing data, emerging categories and theoretical propositions and is argued to be sufficient by Pidgeon & Henwood (1998). Concepts identified in the text in the form of codes considered to be of potential relevance to the research was therefore collected into subcategories using the comparative analysis method (Pidgeon, 1998) and awarded a descriptive label (see Appendix VIII). For example, the quote ‘Well there is something wrong with me...it’s not the kids it’s me I’m doing something wrong’ was placed in a subcategory labelled ‘self blame’. This provided an important resource for later analysis, particularly when specifying relationships between significant concepts became necessary (Pidgeon & Henwood, 1992). This was followed by a focused, selective phase that uses the most significant or frequent initial codes to sort, synthesise and organise large amounts of data by sub-dividing categories or converting two into one resulting in the need to re-label (Charmaz, 2000). For example, internal support/external support/extended family support were clustered together under a sub-category ‘support networks’. The process continued until the core concepts and resulting subcategories were saturated. At this point connections between subcategories were analysed (see Appendix VII) to identify central relationships and how they inter-relate (Pidgeon & Henwood, 1992). This is a similar process to axial coding introduced by Strauss & Corbin (1990). The conceptualisation of a relationship between subcategories led to the emergence of

themes. For example, 'self as alone', 'self as abandoned, self as not valued, self blame, and 'need to be held in mind' formed a central theme 'states of self'. During the process memos were written to monitor different explorations of codes and subcategories and the way they fitted into larger processes.

## RESULTS

The model outlined below is a synthesis of six interviews with parents whose child is currently on the waiting list at the Child and Family service with the researcher's thoughts and reflections on the interview process (see Figure 1). The model illustrates the sub-categories from which the basic concepts and themes of the parents' experiences were formed (see figure 2).

The model will be first described followed by an in-depth explanation and elaboration of the categories that inform the central themes and their interconnections using parents comments to illustrate.

Fig. 1 Model Demonstrating Dominant Themes of Parent's Experiences of Waiting Following a Referral for their child

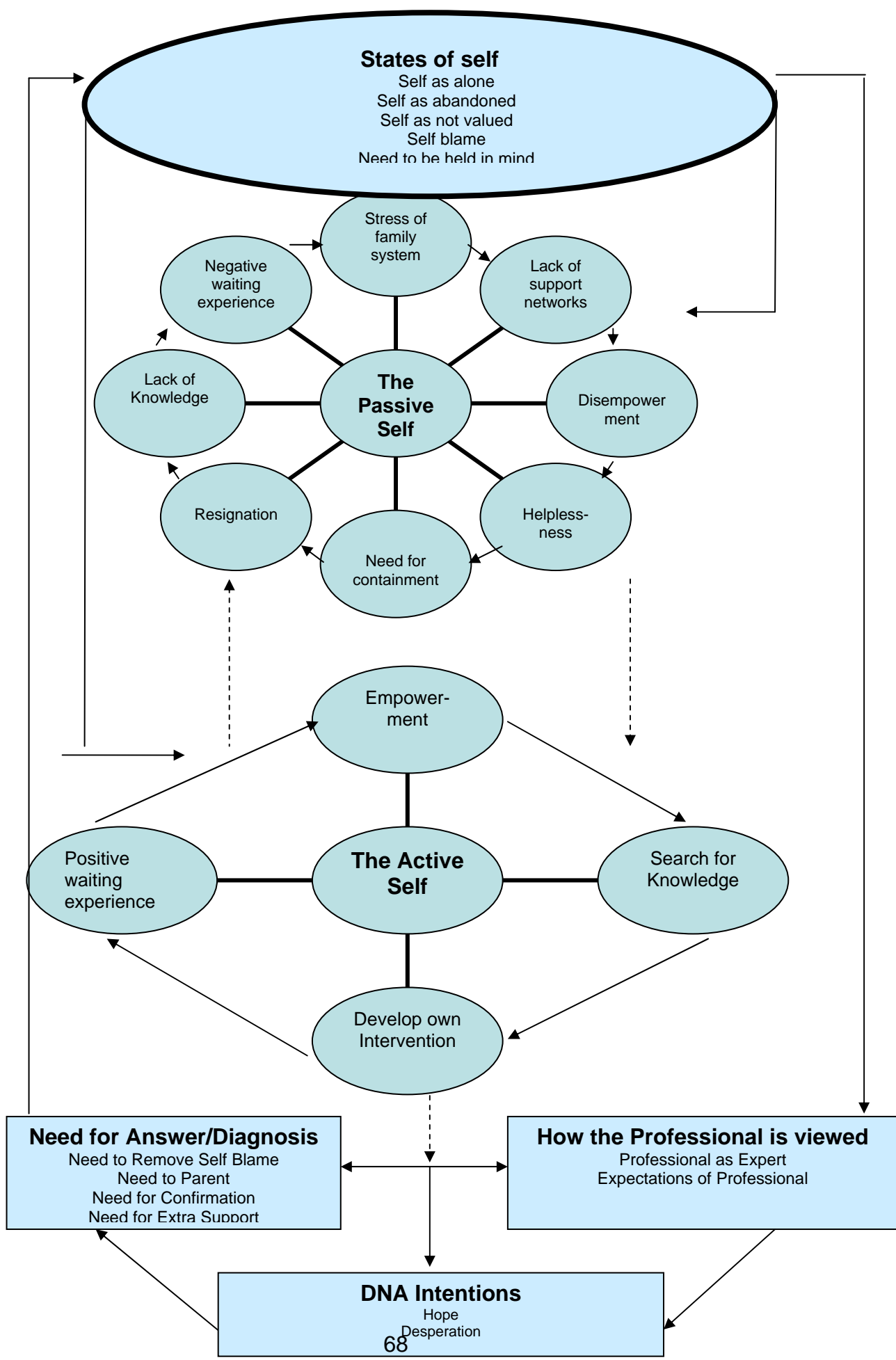


Figure 2 Description of Main Themes and Related Subcategories

**States of Self**

*Self as alone*  
*Self as abandoned*  
*Self as not valued*  
*Self blame*  
*Need to be held in mind*

**The Passive Self**

*Stress on family system*  
*Lack of support networks*  
*Disempowerment*  
*Helplessness*  
*Need for containment*  
*Resignation*  
*Lack of knowledge*  
*Negative waiting experience*

**The Active Self**

*Search for knowledge*  
*Develop own intervention*  
*Empowerment*  
*Positive waiting experience*

**Need for Answers/Diagnosis**

*Need to remove self blame*  
*Need to parent*  
*Need for confirmation*  
*Need for extra support*

**How the Professional is Viewed**

*Professional as Expert*  
*Expectations of Professional*

**DNA Intentions**

*Hope*  
*Desperation*

## **Description of Model**

The subcategories that inform the themes will be underlined and discussed using the themes as headings for reasons of clarity.

### **States of Self**

The term ‘states of self’ encapsulates the subcategorised internal conflicts that were experienced by all six parents. The parent’s described the waiting experience as a struggle to understand what is wrong with their child and what they can do to help. The daily difficulties appeared to be perpetuated by the lack of communication from the service to which their child had been referred. Parents seem to wonder where they went wrong as a parent and feel they are to blame as a result of their child needing to be referred to a Child and Adolescent Mental Health Service. Societal and cultural ideas around the parent being the carer, nurturer, protector, fixer and healer intensify the parents self blame. Parents appear to be aware of a perceived cultural norm from which they consider themselves or their child to deviate. This seems to push them into a state of loneliness. Within this latter state they seem to feel that others do not understand or appreciate the difficulties with which they have to contend. As the waiting time continues the silence from services appears to deepen the loneliness. Parents describe thoughts of being de-valued and feelings of abandonment which appear to be evoked by the lack of communication from services. Thus the silence exacerbates the experience of being alone and is sustained by the belief that no one except the professional, who parents consider to be ‘the expert’, can help. The desperation for help and the belief that the professional holds the answers appears to represent a need to be held in mind by the service.

The model illustrates how parents react passively or actively in response to the internal conflict they experience. The active self and passive self are themes that epitomise the encircling respective sub categories which will now be described,

### The Passive Self

The analysis suggests that those parents who experience themselves negatively adopt a passive stance to the referred problem, which often perpetuates the problem. Parents described how managing their child's problem created stress on the family system. They described the detrimental effect of the problem on the relationship with their partner, other siblings, extended family members and close friends; and how the lack of support networks such as school and related health services disadvantaged their child. Parents found that without a 'diagnosis' or a reason for their child's behaviour they were unable to elicit extra support for their child from the Education or Health Service. Those parents who experienced a sense of disempowerment appeared to feel themselves as locked in to the waiting system, and in being there seemed less able to question or challenge the lack of support services. These experiences perpetuated the helplessness and thus despair. This accordingly exacerbates the need to have some communication or contact with the service to establish the waiting position and time frame as a means and need for containment. As the silence continues the parents' resignation to the process and their child's problem results in a belief that nothing can change until the first meeting with the professional whom they believe will have all the answers. Their lack of information and knowledge of services and professional processes maintains the status quo as the parent continues to endure an unchallenging powerless position and negative waiting experience. The model illustrates how the perception that one is powerless leads to a lack of action which further reinforces

notions of passivity, and this cycle thus becomes a repeating cycle which prevents action in relation to the waiting list, the service their child is referred to and the perceived power of the professional.

### The Active Self

The model illustrates that although all parents experience similar 'states of self' some parents endeavoured to search for meaning and answers to their child's difficulties and thus appeared to adopt a more active approach to the difficulties they were experiencing. Some parents described how they searched for knowledge through the internet, libraries, television programmes and attending support groups. Through acquiring a level of knowledge and understanding parents described how they developed their own interventions such as star charts, other reward systems, and the use of graded positive reinforcements. The desire to have some control over the waiting process and to establish a way forward to elicit change appears to endorse a position of empowerment as the parent continues in the cycle of exploration and development that precedes and supports a positive waiting experience.

### Movement between the Passive Self and the Active Self

The model illustrates how parents do not necessarily remain passive or active as their position changes in reaction to changing experiences. This can be illustrated by using an example from the data. A parent who was in a passive position described a pivotal point for her when on a day her child had been particularly difficult she decided it was necessary to contact the service to find out how much longer they needed to wait and search for information to support the management of her child. Moving from a passive to an active position the parent described how she found attending a support group



useful and consequently felt empowered to look at different strategies and interventions. Based on the same example a parent previously in an active position described how a particularly difficult day left her feeling the interventions she had used were ineffective and therefore reconciled to a passive position of resignation. The move between passivity and activity is demonstrated in the model by dotted arrows.

### Need for Answers/Diagnosis

Regardless of a passive or active position the parents self blame was consistent. Parents expressed a need to know what ‘was wrong with their child’ as this would provide a reason or explanation that removes the cause away from their parenting and consequently remove self blame. The analysis found that parents need to parent and take responsibility for their child, however without an understanding of their child’s difficulties there remains a fear of doing something wrong and worsening the situation. Even the active parent therefore felt the need to have confirmation they are reading the right material and attending appropriate support groups for extra support. Therefore, contrasting the anti-medical model position of not labelling children, the analysis found that the need for an answers/diagnosis was powerful and considered necessary by the parents.

### How the Professional is Viewed

The impetus for an answer/diagnosis amplifies the high regard held for the professional. Parents alluded to the high expectations they held for the professional believing that answers and change will occur at the first appointment. This idealistic view seemed to lead to the idea that at the first appointment the professional would become acquainted with the family script, have an immediate understanding of what

was causing the presenting problem and as a result offer advice that would engender change. The confidence placed in the professional appears to be sustained by a fundamental belief that the professional is ‘the expert’ and therefore will ‘know’ what is wrong, and how to put it right. Parent expectations of the professional being the expert appeared to parallel the expectation one would expect from a ‘magician’, which places immense pressure on the professional and obscures real understanding of the process of therapy and the way the professional is viewed.

### DNA Intentions

The desperation experienced as a result of managing their child’s difficulties perpetuated by self blame, loneliness and a desire to ‘make it right’ and ‘be a good parent’ strengthens the hope placed within the professional and the first appointment. The analysis found that the intensity of the desperation and hope ensures the parents intention to attend their appointment and at no time did any of the parents consider giving up in the form of not attending.

### Linking Categories and Central Relationships

The relationship between the need for an answer/diagnosis, which fosters the view of the professional as ‘the expert’, which consequently secures intentions to attend, is shown by the solid arrows that link the themes together. The expectation on the professional and powerful belief that a diagnosis will eliminate self blame augments the negative view of self categorised under the ‘states of self’. The more negative the parent becomes of themselves the higher regard they have of the professional which accordingly intensifies the negative view of self. This circular dynamic is represented

by arrows around the periphery of the model linking the themes together and showing an incessant association.

### Definition of Themes and Sub categories

The contextual aspects, sub categories, ensuing dominant themes and their interconnections will now be given in detail through an explanation and analysis collated from the parents' disclosures.

### Theme - States of Self

The parents interviewed seemed to experience self states characterised at any one time by feelings and perceptions which have been subsumed under the following subcategories; self as alone, self as abandoned, self as not valued, self blame and a need to be held in mind. All the subcategories, except self blame, reflect the interpersonal relationship between the parent and the service whereas self blame focuses upon an interpersonal insight.

### Self as alone

All six parents experienced intense loneliness. They perceived themselves as alone, and this state was unabated by the presence of their spouse, partners or friends. The waiting amplifies and intensifies the loneliness as each day becomes increasingly difficult to manage: *"Gutting... it's really upsetting because you think I am no nearer than I was 3 weeks ago although you expect it because no miracle is going to come there is a list and you do have to wait your turn but its just sort of... please help somebody!!!"* (Interview 5: 667 - 676). The parent has no alternative but to try and manage. Desperation for some level of contact or advice to alleviate the loneliness

was evident throughout the interviews: *“when you are on your own it’s just... like I said it’s just hard, very hard I just don’t... I never know which way to turn”* (Interview 6: 448 - 449)

### Self as abandoned

Loneliness appeared to be augmented by feelings of abandonment. Four parents expressed a sense of being forgotten in terms of feeling deserted by the service: *“as soon as they referred me there has been nothing. It has literally felt like we have been ‘dumped’. There has been no letter to say that I was now on the waiting list for Child and Family Service”* (Interview 3: 67 - 72). Consequently, parents feel lost in the ‘unknown’ and left to wonder why their appointment has not been forthcoming: *“you’re sitting there panicking, thinking ‘well maybe something has gone wrong, maybe I have slipped through the gap, maybe I have not received the appointment, maybe they have not received the referral from the consultant”* (Interview 4: 604 - 610).

### Self as not valued

Two parents felt that the process left them feeling undervalued. The perception of these parents was that their difficulties were viewed as insignificant by professionals; this appraisal appeared to increase their experience of loneliness and abandonment: *“you are being told ‘oh its an 18 month waiting list you are on the list you will get seen when it is your turn... there are people coming in that need to be seen before you”* (Interview 5: 368 - 370).

## Self Blame

The intensity of loneliness, abandonment and feeling undervalued seemed to evoke feelings of vulnerability which in turn seemed to create a milieu in which self-blame could flourish. It was as though the absence of a containing therapist able to modify attributions and provide more helpful alternatives left parents' with no alternative but to continue searching for their own answers, and to find them within themselves in terms of self blame. This was expressed by two parents: "*well there is something wrong with me – it's not the kids it's me I'm doing something wrong*" (Interview 5: 634 - 636); "*I blame myself all along because no one would give me no answers to the way she was acting, behaving and being with me...*" (Interview 6: 59 - 62).

The intensity of the negativity of parents' views of themselves was overwhelming. At no point during the interviews did any parent allude to a positive description of themselves. Despite this it became clear that participants either adopted a proactive or passive position in relation to finding their own answers. The proactive parent, themed as the 'active self', tended to search for knowledge to increase their understanding and develop their own interventions in a bid to change the status quo; whereas the parent adopting the 'passive self' were inclined to become resigned to the problem and to subsequently feel disempowered?

## Theme - The Passive Self

The term passive is defined as 'accepting or submitting without resistance or objection' (*Stedman's Medical Dictionary, 2002*) and is used here to describe an inactive position within which the parent feels unable to exert influence to change the situation they experienced. The passive parents experiences the waiting time

negatively and appeared to see no alternative but to continue waiting for an initial appointment whilst the referring problem and their parent /child relationship continued to deteriorate. Their experiences seemed to suggest eight sub categories.

### Stress on family system

Five of the six interviewee's stated that the waiting experience had caused stress within the family: *"it's affecting others it's made my son react negatively so we are concerned about how it's affecting him and ermm it does make tensions in the house... it's difficult to know how long the family can continue as it is"* (Interview 1: 46 - 52).

Interviewee 5 gave insight into the stressors of the parent/child interaction: *"I mean you do sit there and as horrible as it sounds you get to the point where you don't like your children"* (326 – 330). Note that the word 'children' is mentioned here as opposed to just the referred 'child' thus giving insight into the waiting experience, the way the self is viewed and how this affects the interaction and relationship between the parent and other siblings. One parent touched on the relational stress experienced between herself and her husband by suggesting a service development that would include her husband so that he could gain an understanding and appreciation for the immense difficulties she faced each day: *"But I wish there was something (evening appointments to included dad) because I always think things like this are always aimed at the mums or the main carer. But if he (dad) could be involved in something it would make him understand easier"* (Interview 3: 496 - 500). The stress experienced within the family system evokes a need to incorporate support from other support networks.

### Lack of Support Networks

Only two of the parents live close to their families and therefore were able to elicit some support. Interview 2 stated; *“my mum tried to suggest an alternative that my daughter slept at their house ermm... to give us all a break”* (118 – 121). Similarly interview 3 expressed; *“it is very hard for other people to understand... but my mum and dad are about the best. I will go and actually stop there for the night”* (379 – 386). One parent found support in friends; *“Oh Yes they [friends] have been like a release for me because I have like spoke to them when I have been feeling low and stuck and don’t know what to do”* (Interview 6: 589 - 592). However, although family and friends were reportedly a help at times, the analysis found the support to be transient and not sustainable enough to reduce the stress experienced by the parent and their family system. The ineffectiveness of the support from others in terms of reducing stress within the family home was evidenced by four of the parents including those who had cited friends and family as providing support. Reference was made to the fact that in reality, and in relation to what they needed due to the stress experienced, they did not, in effect, have any real and sustaining support. Interview 3 who had previously described her mum as supportive stated *“They don’t see the inside they don’t see what we have at home, what goes on when the door is shut”* (365 – 367). Similarly interview 6 who had reported finding support in friends concluded; *“My family live in X ...we’re not that close to their dad’s side... so no there were no one really”* (157 – 159). The analysis concluded that insufficient or absent support networks unsurprisingly do little or nothing to support the family or decrease the stress they are experiencing. The danger is that the absence of support perpetuates the parents’ negative view of self and this consequently leads to disempowerment and a sense of helplessness.

## Disempowerment

Disempowerment is defined as ‘a deprivation of power’ (What Do Words Mean, 2006). As the waiting time continues the parent becomes disempowered and feels less able to take control and change their situation; “*just to give people an understanding (of how long they have to wait) rather than making them feel that they are being stuck out in limbo*” (Interview 4: 521 - 525). The analysis suggested that it is the position of disempowerment that prevents the parent from challenging the professional and reclaiming the power they feel remains with the professional and the service to which their child has been referred; “*when he was referred by occupational therapy... and I just thought – well – it’s awful because I keep looking at it in my diary thinking I really should do something about that but I don’t know what, because there is no phone number and I don’t want to bother the Occupational Therapy department because I know their department is very busy*” (Interview 3: 769 - 780). The irresolute experience of disempowerment results in a loss of control and a failure to assert oneself, despite the immense pressure and difficulties managing the child who has been referred, and consequently subjects the parent to a feeling of helplessness.

## Helplessness

A clear description of helplessness in the sense of feeling unable to do anything to help oneself was found in four out of the six interviews; however the concept was suggestive in all six interviews. One parent spoke of the despair and awareness of being lost; “*Sometimes it feels like being in the middle of a tunnel and there is no light*” (Interview 1: 123 - 124). This was reiterated by interview 6 “*it just feels like we are going round and round and round and just not... there is no leeway, no way out*” (468 – 472). Within the disorientation of being lost the helplessness intensifies the



powerlessness inhibiting the parents' perceived ability to cope; *"You feel like they are getting worse and you don't know what to do. I have times when I have sat on the stairs crying because they won't walk home from school and I have thought I can't do this every day of the week its driving me mad"* (Interview 3: 824 - 831). The helplessness impinges on the development of strategies and interventions to make change or manage the presenting difficulty; *"there is nothing else that us as a family unit can try so... we have thought of every thing possible we can"* (Interview 2: 209 - 212).

### Need for containment

The disempowerment and sense of helplessness evokes what appears to be a need for containment. Parents described how they would welcome some indication of where they were on the waiting time or just an initial contact with the service; *"perhaps if there could just be more of an initial contact, or a personal visit from somebody just to let us know just how long its going to be or you know... so, just so we've got something to aim for – to look forward to - time limit or something"* (Interview 2: 169 - 175). All six parents expressed a need for containment in the form of having some idea of how long the wait would be *"If every time a referral was made if you just got a little note back saying ' we have received a referral from (name of consultant) we will be in contact with you in the near future for your records please be aware that the waiting time is however long' then I think people would be more inclined to...this would be helpful"* (Interview 4: 611 - 620). The analysis found that the 'not knowing' is as difficult as 'the waiting'. This suggests that steps to contain the family by keeping them informed of their progress on the waiting list may resolve some of the negative experiences they encounter. In the absence of this, parents endure desperation within

what feels to be an enduring abyss; *“Erm... desperation. I just need to know that something is being done. I am... they know my name...they know that this child is on the list and it needs to be seen* (Interview 5: 645 - 651). The desperation experienced by the parent and the lack of perceived containment whilst in a passive frame creates an extensive gulf between the parent and the professional and hence leads to a position of resignation.

### Resignation

The process of becoming resigned to the waiting situation is closely linked to the experience of disempowerment and helplessness. Five parents described their submission to the problem in relation to the system; *“You get to the stage where you start living with it but it has not resolved but you do start living with it and you make allowances for it”* (Interview 1: 27 - 31). Within the passive position parents become resigned to the waiting as opposed to fighting the system they perceive as having the answers; *“its just a waiting game really I have to sit and wait for that letter to come through the door”* (Interview 3: 78 - 80). Considering, according to the interviews, how difficult it is to manage each day with their child who has been referred one would expect that the desperation would be sufficient to urge the parent to challenge the system or at least endeavour to find out when an appointment is likely to be forthcoming. On the contrary, the analysis found that parents continue to wait in a passive powerless position until the service makes contact; *“As I said [waiting] it is something you just get used to it”* (Interview 4: 142 - 143).

### Lack of knowledge

One of the reasons why the service remained unchallenged by the parents was their limited knowledge and understanding of the referral process and the service to which they were referred. Without information and knowledge of services and the referral process, parents remain in a position where they are unable to challenge the status quo due to a lack of understanding and expectation of what constitutes acceptable waiting times and good practice. One parent explained how she had waited until the problem become unmanageable and thus sought her GP believing she/he was the professional person to help; *“its just the time its like going to the GP I didn’t realise that the GP was just the first stage. Ermm... by the time I went to the GP I was already really quite upset with the situation feeling that it was out of control and I didn’t realise that that was just the first step”* (Interview 2: 64 - 71). A lack of information regarding the service to which their child is referred intensifies the passive position in terms of how to challenge and assert oneself; *“So then they suggested to me what they were going to do ermm was go to put J on a waiting list – refer him to Child and Family Service which I’m not being rude I had never heard of before, didn’t know what they were, who they were, what they did or what they could do for me”* (Interview 3: 46 - 53). The difficulty for parents to challenge the service regarding an impending appointment is increased through a lack of knowledge and consequently further disadvantages the parent resulting in strengthening a passive position.

### Negative Waiting Experience

All six parents described the waiting experience in negative terms. One parent described the wait as an enduring never-ending entity; *“Yes so it is real... it’s a really difficult time. I can’t remember how long we have been on the waiting list for,, it just*

*seems like forever*” (Interview 3: 107 - 111). The negative experience is closely related to some of the subcategories informing the theme ‘States of Self’. The parent in interview 5 alluded to the way in which the waiting intensified the negative view she had gained from the experience in terms of blaming herself, feeling abandoned and undervalued; *“You just want to find the answer. You just want to know is it just me? Am I a bad mother? Is there something wrong with my child? Or is there something more? So that’s really sort of the negatives I think it’s the not knowing and the keep hearing ‘oh well there is a waiting list... you have to wait your turn”* (Interview 5: 136 -147). As the wait continues the stress on the family system begins to tell; *“So I think we have waited so long it has brought a wedge between us”* (Interview 6: 427 - 430). The waiting time therefore appears to be negative in two ways: it perpetuates the experiences highlighted in the sub categories and intensifies the stress on the family system.

The negative experience is exacerbated by being caught in an inactive, passive dynamic as outlined by the sub categories. However, the analysis found that four of the parents experienced a shift from a self-state of disempowerment to one of empowerment. The experience of helplessness and disempowerment appeared to act as a catalyst for some parents’. The need to search for information regarding the difficulties they experience with their child prompted a process of control reclamation which led to the establishment of other management strategies.

### Theme – The Active Self

The term active is defined as ‘disposed to take action or effectuate change’ (*WordNet, 2003*). As categorised earlier all six parents passively experienced the waiting list as

negative. However the analysis found, at times, that four of the parents due to the stress they experienced became active by empowering themselves to search for information on their child's problem and develop their own strategies in a desperate bid to initiate some change and alleviate the ongoing stress. The feeling of empowerment when valid information and successful strategies were formed led to the parents viewing the waiting lists more positively. There are four sub categories that inform 'the active self' theme.

### Empowerment

Three of the parents described times during the waiting experience where despite their daily struggle and stress they were able to see positive aspects of their child as opposed to always seeing the difficulties; *"I am lucky, I have a boy and a girl – both healthy... they are different but they are both healthy. They can both talk and tell me what they want"* (Interview 3: 640 - 644). When seeing the situation through a different lens the parent moves from a position of helplessness to a state of empowerment and consequently regains some level of control. This appears to strengthen the parents' resolve to fight for their child's needs to be met; *"So I have had to go on a battle and fight with the school that he is at to get things put in place, and I have had to do that myself"* (Interview 3: 91 - 95). Whilst in a positive frame of mind the parent not only recognises the injustice and imbalance of power between self and the service they feel empowered to challenge and fight for what they need; *"No just left... I am just left waiting... if I'm not given a date and haven't been got in touch within a certain time then I will ring up. Then I will ring up and keep pestering and pestering until I get something"* (Interview 6: 500 - 508). Shifting to a positive position therefore empowers the parent to act accordingly on behalf of their child to get the help they feel

is desperately needed. Unfortunately this does not change their child's position on the waiting list, or result in a sooner appointment; however the sense of empowerment appears to encourage a drive to search for answers which would resolve the problem.

### Search for Knowledge

Four of the parents shared how they had at times tried to be proactive in searching for information that might give them insight and answers to the problems their child is experiencing; *"The only thing I can say to that is the fact that because I'm waiting I have had to search out my own information which has just made me more confident"* (Interview 3: 314 - 318). The confidence alluded to again encourages the parent to see their child differently and respond to them differently; *"Instead of yelling and screaming and wondering 'what is the matter with you' you are more sort of tolerant of a few things because you sort of read the books just in case this is what is wrong so your more aware of how things happen why they happen and strategies to sort of kind of help when they do have them"* (Interview 5: 47 - 57). The search for knowledge enabled the parents' to have an understanding of what underlines their child's behaviour and this knowledge encouraged the development of coping strategies and interventions to alleviate some of the difficult behaviour of their child.

### Developing own intervention

Three parents described how from their search for knowledge they developed strategies and used them to cope while waiting to see the professional; *"and I... if I have a problem I put in my own structures at the moment... so I had a problem with both of them wanting to be first to have a wash my little boys nearly 7 and I still have to wash him and brush his teeth. I can't do both of them at the same time so I*

*organised a chart. Every other day he goes first and on the other days she goes first and it works”* (Interview 3: 226 - 228). Having a different understanding from reading and researching the problem promotes a more positive way of parenting; *“Yes, Yes a lot of it is the way that you talk to the children because if they do something you are more likely to sit down calmly and take a deep breath and talk to them rather than just rear up and ask ‘why did you do that “So yes it kind of gives you strategies to think about rather than just act.”* (Interview 5: 74 - 83). Implementing ones own interventions and strategies appears to endorse a positive view change and subsequently it could be hypothesised that this would lessen the stress within the family system. The process of empowerment and creating interventions from gained knowledge leads the parent to experience some of the waiting time as positive.

### Positive Waiting Experience

Three out of the six parents reported some positive aspects from waiting based on what they had discovered and implemented for themselves; *“Positive? Just the fact that you try and deal with things yourself, you try and seek out information yourself to try and see what you can do to alleviate it”* (interview 3: 866 - 870). The same three parents also discovered different parent support groups in their search which offered understanding and support from other parents experiencing similar difficulties; *“So that’s positive because like I said without the waiting list I didn’t know these groups existed so... I was just on my own with no help sort of thing”* (Interview 5: 582 - 587). Interestingly, two parents described a positive feature of the waiting list as the waiting list itself and its implicit perceived message; *“’Cause (sic) if there is a waiting list that long then there is obviously a problem in general rather than just with my specific child”* (interview 5: 17 - 21). This parent found comfort in comparison that

she was not the only one to be experiencing difficulties with her child. Given that the same parents also cited negative aspects of being on the waiting list it is evident that parents experience mixed emotions which appears to be caused by moving between passive and active states during their wait, as demonstrated in the model. The issue that seems to pivot the parent between the passive and active self is a strong need to have an answer or diagnosis as an explanation of their child's difficulties.

### Theme - Need for Answers/Diagnosis

Central to all parents' experience of waiting was the need to know, and concern about, what was wrong with their child. In counselling psychology we steer away from diagnosing and diagnostic labelling (Pilgrim, 2000) however what was evident from the analysis was a strong need of the parent to have an answer, or a diagnosis, to confirm what the problem is, and assurance that they are using the right strategies for positive change. There were four sub categories demonstrating the need for answers/diagnosis.

### Need for Confirmation

For the active parent who has strived to search for knowledge, and to develop strategies to manage their child's difficulties the fear of doing something wrong is paramount: *"although you are sort of sitting there and trying out the strategies and things that internet and books tell you its still because you are not 100% sure that this is what is wrong – am I doing it right – am I doing more harm than good? Is this working – is this not working?"* (Interview 5: 700 - 710). The fear of not knowing or exacerbating the situation not only hinders the implementation of strategies but serves as a catalyst for the parent reverting back to a passive position.



### Need to Parent

Not having an answer intensifies the feeling of disempowerment and helplessness; not only does the parent have to come to terms with their perceived belief that there is something wrong with their child, their natural parental instinct to look after and nurture their child is hindered; “...when you haven’t got a firm diagnosis as to what is wrong with your child it is very limited to.... basically know what is open to you and where to go. So until you have got that it is very hard to know what to do for yourself and for the family” (Interview 4: 11 - 22). The consequence of this is further stress on the family system locked within the perpetual negative dynamic of the passive self.

### Need to Remove Self Blame

Self blame is augmented through not having answers or a diagnosis and consequently reinforces the belief that the self is to blame; “Well yes they did say it were (sic) not my fault and nothing to do with me but then they didn’t give me any answers as to why things were like this, you know it were just the way she were” (Interview 6: 298 - 304). Without a reason for their child’s behaviour the parent feels there is no alternative but to blame themselves. This subsequently deepens the experience of loneliness and abandonment and again maintains the passive role engaging in the corresponding cycle as described earlier.

The need for answers/diagnosis is therefore perceived as essential to the parent.

Whereas the counselling psychologist may view a diagnosis as unhelpful/inappropriate labelling, the analysis found that the parent sees it as an answer. A diagnosis serves the function of confirming what they are doing is right, helps to identify how to best look after their child and provides an answer to the question of what is wrong with

their child, thus removing elements of self blame. However, the desire for an answer or diagnosis shapes the parents expectations of the first appointment, in that they anticipate that the professional *will* have the answers and provide interventions to effect an immediate change.

### Theme – How the Professional is Viewed

It could be hypothesised that experiences of feeling alone, abandoned, undervalued and at fault would evoke negative feelings towards the professional due to prolonged waiting, the professional in these terms meaning the Child and Family Service clinicians. However, this did not seem apparent through the expressed expectations the parents had of the professional, which remained constant throughout all the interviews both when the descriptive self was passive and active. Parents viewed the professional as ‘the expert’ and believed they not only hold the answers as to what was causing their child’s problems but also what would make them better.

### Professional as Expert

All six parents viewed the professional as ‘the expert’ and even more concerning appeared to believe that the professional would be something akin to a magician with ‘tricks up his sleeve’ in terms of having all the answers; “*(seeing the professional) ...is knowledge from other people that have seen thousands of different cases of what my children have got... there comes a time when I need someone else to say ‘let me look at it from my point of view, how about you try this’*” (Interview 3: 297 - 304).

One parent felt that the benefit of seeing the professional far outweighed the long wait and all the stress and difficulties experienced as a consequence; “*At the end of the day my children’s needs outweigh any waiting list and their needs are paramount so even*

*if I had to wait a year or 2 years I would wait that 1 year or 2 years because at the end of the day I know what they are going to get will be beneficial for them and that is the most important thing*” (Interview 4: 293 -302). The fact that a parent is prepared to wait 2 years because of a belief that the professional will make a big difference places immense pressure on the unsuspecting professional. This may have consequences on the development of the therapeutic relationship and outcome.

### Expectations of Professional

There was also high expectation that not only would the professional solve the problem but it would happen immediately. Therefore all hopes are pinned on that first, almost magical, appointment. The expressed belief was that the professional will have all the answers and these will be given immediately; *“Well the closer you are to be seen the more upbeat you are so the more sort of relaxed I suppose to certain elements of the problems.... There is light at the end of the tunnel, we are nearly there, we are nearly there”* (Interview 5: 117 - 128). The expectation on the professional increases the internalisation of the interviewee's view of self and consequently their feelings of inadequacy to initiate their own ideas and management *“obviously you don't know how to deal with them until you go to the relevant people or see the relevant people and get guidance that you do need”* (Interview 4: 326 - 331). This dynamic increases the expectation that the professional is the expert and correspondingly the expectations of the initial appointment. These high expectations and the high positive regard for the professional sustain feelings of inadequacy and self blame which may, as a consequence, result in disempowerment and reinforce the passive self cycle.

## Theme – DNA Intentions

In general the analysis found some positive experiences of being on a waiting list however in its entirety the experience was reported as negative and unconstructive. Given this conclusion it could be hypothesised that parents' are more likely to become disillusioned and consequently decide not to attend. Interestingly this was not the case as all six parents affirmed their intentions to attend regardless of the length of time waiting. Significant to this assertion is the idealised view of the professional and the hope that they will find answers to ease their desperation.

## Hope

What would seem to be the fundamental reason for the parent's ongoing distress, that being the waiting, is paradoxically the same that provides a method of coping. It offers the hope which parents cling onto when they feel unable to manage their child; "*(being on the waiting list) you've got something to look forward to that its going to be resolved ermm...how ever long it is going to take*" (Interview 2: 221 - 224). This being their perceived only hope precedes their intention to attend an appointment supported by the view that they will find answers and their child will 'get better'; "*I am not giving up now I am this close there has to be answer somewhere*" (Interview 5: 188 - 192). In the same way the view of the professional feeds into a conviction of hope, the parents' negative self state intensifies the desperation that also affirms intentions to attend.

## Desperation

Desperation is defined as feeling that you have no hope and are ready to do anything to change the bad situation you are in (Cambridge University Press, 2006). The parent's

desperation leading to a determination to attend signifies the hope they have lost in their own ability as a parent in relation to managing their child's problem and projects a desperate need to attend "No! I'm not giving up now. It took me a long time to get my husband to agree there was a problem. I have been telling him since he was 2 and he is now 9 so its sort of took this long" (Interview 5: 184-187). The parents' loss of hope and belief in self accordingly strengthens the hope placed in the professional which serves to validate the experience of desperation and subsequent disempowerment; "no, no, no. I'm not...like I said I can't carry on like this any longer something's got to be done" (Interview 6: 242 - 245). Despite the desperation the professional is still seen as the person with all the answers, which ensures attendance to the appointment. Because of the high regard held for the professional, the parent has nowhere to vent their frustration and consequently the frustration, anger and desperation internalises and may endorse the negative states of self as discussed earlier.

### Concluding Comments

The data has shown that the waiting experience is fraught by the loneliness and abandonment and self blame the parents' experience resulting in an interchanging role of being active or passive and the subsequent cycle they subside into. What the model illustrates is a wide disparity between the way the parents view themselves and the way they view the professional. This is because of the need to believe that someone can help make a difference to their child and their situation. The disempowerment and self blame that is perpetuated through waiting intensifies the parents' helplessness. Some parents use the waiting time effectively by searching for their own answers but may eventually become passive following a belief that their parenting is not sufficient

and professional help is need. The overall experience may be negative but hope and belief in the professional's ability is what appears to keep the parents' encouraged; "*(It just... it just... from what you are saying it just sounds like that first appointment is just so crucial?) Yes! (You're hanging on just for that?) Yes!*" (Interview 5: 526 - 534).

## DISCUSSION

This research had two aims, the first was to gain an insight into the way parents experience and manage the time they are on the waiting list of a Child and Adolescent Mental Health Service, and the second, to use this information as a basis upon which to consider improvements to the service. Previous research suggests that long waiting times are closely related to poor attendance rates as clients who have waited excessively are less likely to attend (Rawlinson & Williams, 2000). Paradoxically non-attendance of initial assessment appointments is a major contribution to the maintenance of high waiting lists (Stallard & Potter, 1999). On the basis of this it was hypothesised that there may be a need to make changes such as implementing a system to support parent's through the waiting process to encourage continued interest and attendance. Of equal importance, and from the standpoint of counselling psychology, it was anticipated that an understanding of the waiting experience would provide information the counselling psychologist could use to promote a positive beginning and therapeutic alliance.

There is currently very little research based literature examining parent's experiences of waiting for an appointment, and what research there is has not moved the agenda of service development forward, particularly with regards to meeting the mental health needs of children and young people (Rawlinson & Williams, 2000). The absence of movement may be an artefact of the current research focus on utilisation of a hypothetico-deductive epistemology to accept or refute researchers' pre-conceived hypothesis. To address this deficit a phenomenological methodology was adopted for the present research as a means of understanding and generating theory, grounded from

data acquired by asking families about their experiences of waiting for their first appointment. This discussion examines the emergent themes (see figure 1) in relation to existing literature and will be followed by recommendations for service development and clinical delivery. Finally, limitations of the present research will be discussed and recommendations made for future research

### **States of Self**

Parents encountered a changeable journey of positive and negative experiences whilst waiting for their child's initial appointment. One experience which seemed to form a prominent theme in parents' discourse about waiting was the effect on the parents' concept of self and their self-efficacy. It is generally accepted that the intuitive parent knows what is wrong with their child and can comfort or alleviate their distress. This process may be achievable with a child's physical problem, which by its very nature is evident, but may be more difficult with mental health problems which are much less easily observed. Thus when parents are unable to fulfil this role because of the nature of their child's difficulty it appears that they experience overwhelming feelings of loss and inadequacy, which may well be the foundation for the onset of experiences leading to the negative states of self as demonstrated in fig. 1.

### **The Passive and Active Self**

Rogers (1951) contended that psychological disability results when persons are prevented from being who they truly are. In this sense it could be argued that a parent who is thwarted in their drive to help their child is similarly being prevented from being who they are and this may exacerbate any negative ideation about the self. In a



similar state of 'psychological disability' the findings of this inquiry found parents move between states of passivity and negativity, which is effectuated by a drive for empowerment and hindered by a lack of knowledge in relation to 'what is wrong' with their child and how they can 'make it better'. Activity and passivity and the movement between these concepts appeared to be central to parents' experiences and the discussion is thus based around this. To explore this it is necessary to consider theories of personality.

Psychoanalytical theories of human nature postulate that behaviour is governed by irrational and unconscious psychological forces suggesting that we are in essence passive agents (Freud, 1927). Likewise radical behaviourists claim that we are passive beings shaped by interactions and learning experiences, which mould our action through trial and error reinforcement (Watson, 1913). In direct contrast humanistic and cognitive social learning theories depict the self as an active agent arguing that what we think about the world, what we learn to expect from others and what we imagine we can do, shape our realities (Maslow, 1970; Buhler, 1971; Monte, 1999). Personality theorists would therefore have us believe that the self is either passive, or active as opposed to interchangeable (Monte, 1999). However, Buss (1978) argued that neither theory is satisfactory as people are both subject and object, active creators and passive recipients of stimulation. The present research points towards an agreement with Buss (1978) with the findings that individuals are active *and* passive, and therefore suggests that something other than basic personality causes us to behave in, and move between, active and passive ways. The research indicates that it is particular events or stimuli that evoke these shifts in behaviour. Reflecting on the interview experience I contend that it is intense emotion following an occurrence that

elicits a positive or negative reaction that appears to act as a catalyst for movement between activity and passivity. The same occurrence can be the precipitator for change in both directions. For the active parent, despite all the knowledge and support ascertained, a crisis can result in a shift from activity to passivity as the parent moves into a state of feeling powerless, which as a consequence shifts the parent into a passive self feeling helpless, disempowered and resigned to the wait to see the professional. For the passive parent the same incident and subsequent feelings may motivate a drive to search for knowledge to alleviate the stress and a desire to regain some control and hence reposition the parent into an active self.

A major factor that was found to be contributing to the maintenance of passivity is the levels of stress experienced within and between the family system. Stress occurs when the demands are greater than the resources available to meet those demands (Lazarus, 1976; Lazarus & Folkman, 1984). For parents in the passive position, resources such as informed knowledge and adequate support networks were found to be limited which contributed to their levels of stress. Perpetuated further through a sense of disempowerment, parents assume an external locus of control, which according to Rotter (1966) underpins a belief that they have limited or no influence to change their situation. The opposite was seen in parents in times of activity where they searched for information and attended appropriate support groups, hence assuming an internal locus of control. Rotter (1966) posited that locus of control is on a continuum and not bi-polar. Perceptions of control increase the ability to deal with frustrating situations and thereby reduce anxiety and stress (Palmer, 2003). Thus it may be that parents who had predominately taken an active position experienced a positive waiting experience. Conversely, little or no perceived control can increase anxiety and depression, and

negatively affect psychological health (Palmer, 2003), thus accounting for the negative experience reported by parents holding a passive position.

### **How the Professional is Viewed**

The analysis found that whilst the parent was in an active role they endeavoured to search for knowledge and develop self strategies to manage their child's behaviour, however when in a passive role they appeared to experience a sense of resignation, viewing the service as their only source of help. It may be that providing information at the point of referral which included sources of self-help and support could move a passive parent into activity; thus influencing the manner in which the professional is viewed. It appeared that as parental self-blame increased, expectations of the professional likewise amplified. This appeared to lead to a situation which highlights a disparity between the magical view parents have of the professional and the 'demoralised' professionals' referred to by Rawlinson & Williams (2000). It also highlights a discrepancy between parental expectations and what the professional, according to their theoretical stance, may be able to offer in an initial appointment. It may be important to consider, in terms of the initial engaging, that the belief or hope that the professional will hold all the answers could be based on the power of the medical model (Pilgrim & Roger, 1996), which may be heightened by the current plethora of television programmes involving psychologists as experts going into homes and successfully changing difficult child behaviour. Although arguably good in relation to providing strategies to inform parents on behaviour management, the possible consequence for parents is the increase in idealisation and expectation of the professional.

### **Need for Diagnosis**

The analysis found that the need for answers/diagnosis appeared to be underlaid by a desire to diminish self blame. However there may be a possibility that a belief in the professional holding all the answers prevents the passive parent from considering their own answers and reasoning, and positions them where they feel unable to take any control. Even the parents who adopted an active role doubted their own intuition when searching for information. It may be that as Seligman (1975) contends in his theory of learned helplessness there is a connection between such learned helplessness and passivity leading to a lack of motivation and a general apathy in which no efforts at all would be made to do anything.

### **DNA Intentions**

Current research contends that parents' who have an excessive wait for their child's first appointment are less likely to attend (Stern & Brown, 1994; Stallard & Potter, 1999; Rawlinson & William, 2000). The implication here is that it is the length of wait that influences the parents' lack of intention to attend and little regard has been given to other possible factors. All parents' interviewed in the present research stated that despite their wait they had no intention of not attending their appointment, which appears to refute current research hypotheses. Parents described the waiting experience as a time of desperation, however they also depicted the wait as a symbol of hope as they viewed the length of waiting as suggesting that there are many other parents experiencing difficulties with their children and the service must not think their problems are serious if they are allowing them to wait. Parents quite clearly communicated that not only do they expect to wait but that they are happy to wait as long as they have some idea of the waiting time and are kept informed of the waiting

progress. This is a contradiction to the findings of Robin (1976) and Jaffa & Griffin (1990) who argue the significance of a two week threshold before DNA rates increase. It would appear that it is not the length of waiting that discourages attendance but rather a lack of clear and consistent communication from services to parents keeping them informed of their position on the waiting list. It may be, therefore, that parents who DNA have lost hope due to a lack of communication rather than a reduced willingness to attend an appointment (Robin, 1976).

Jaffa & Griffin (1990) found a significant increase in attendance when appointments were given within a two-week threshold while the family were still at crisis point. Relating this to the present findings parents might be more responsive if they have not developed a passive position, however the parent taking an active role may be prevented from discovering and developing their own resources, which may lead to empowerment as opposed to reinforcing their dependence on services and professionals. Therefore the suggestion of effective intervention being lost due to delayed appointments (Jaffa & Griffin, 1990) is not wholly supported.

Plante and Meloche (1977) found that offering one face to face contact promptly following receipt of the referral resulted in 20% of families needing no further intervention. As with Jaffa & Griffin (1990) this could be because families were seen whilst still in an active position however as the analysis has shown it could be because information was provided which would serve to empower the parent and encourage a sustained active position.

## **Implications for Service Delivery and Clinical Practice**

Exploring the parents' experiences of waiting for their child's first appointment has led to an understanding of the difficulties and challenges parents face on a day to day basis (see model fig.1). Previous research has identified the length of wait for an initial appointment as the prime factor for not attending (Stern & Brown, 1994; Stallard & Potter, 1999; Rawlinson & William, 2000). All parents interviewed in the present research assured their full intention to attend despite the length of waiting however the analysis of their experiences has found there are other factors that are important in considering why others may DNA. To improve service delivery and encourage a positive beginning and therapeutic alliance the following recommendations based on the research findings are made:

### **Service Delivery**

1. High levels of stress that are experienced by the parent in a passive position leads to disempowerment and results in an external locus of control enforcing a belief of having little or no control over situations (Rotter, 1966). Stress occurs when demands are greater than the resources (Lazarus, 1976; Lazarus & Folkman, 1984). To encourage an active participation and empower the parent, services need to provide relevant and useful information on the referring problem and information on appropriate support groups in an attempt to match resources to the demand.

Knowledge and support was found to be effective for the parent when in an active role and if provided before the 'two-week' threshold (Jaffa & Griffin, 1990) may prevent the parent becoming passive and hence avoid the consequential negative cycle. One suggestion would be to send information that matches the problem described on the referring letter; however personal clinical experience suggests that some referrers do not provide comprehensive information from which a valid judgement on the

presenting issues can be made. The danger of this is that wrong information could be sent that confuses matters and inadvertently set the parent up to fail, which may encourage passivity. In view of this a model such as that suggested by Plante and Meloche (1977) of separating screening from assessment is recommended to provide an initial face to face contact where information can be taken of the presenting issues, a decision can be made as to whether the service is the right service to meet the needs and the severity can be assessed to assist clinical prioritisation. If deemed an appropriate referral, information could be provided to empower the family or information given on other suitable sources of support as well as information about the service and expected waiting times. When inviting families to a face to face appointment it would be important to make the purpose of the meeting clear to avoid unrealistic expectations.

2. Providing an appointment within a two-week threshold as argued by Jaffa & Griffin (1990) may increase attendance rates but could prevent the active parent from discovering and developing their own resources reinforcing dependence on services and professionals. Therefore recommendation 1 to separate the assessment and intervention stage (Plante and Meloche,1977) where a face to face appointment was offered soon after receipt of referral, would give parents opportunity to develop their own ideas from the information given at the initial appointment and encourage activity, empowerment and subsequently reduce dependency.

3. It was found that parents move back and forth between states of passivity and activity and that the movement is usually initiated by a crisis. This is important as far as service delivery is concerned as it provides an opportunity to empower the parent

accordingly. By providing a contact number to access the service parents who felt in crisis could make contact for support. For the previously passive parent who becomes determined to change their situation relevant information could be provided from the service to empower and encourage a continued active state. The same telephone support may prevent the previously active parent from entering the cycle of passivity (see model fig. 1). The information gathered from an initial face to face appointment would elicit an understanding of the family's difficulties and help inform the advice offered by the clinician taking the call. As in recommendation 1, clear information regarding the telephone service would be important in terms of it being a method of support as opposed to a therapeutic intervention.

4. A further factor that reinforced the passive cycle was the perceived gulf between self and the service perpetuated by a lack of communication. The transcriptions revealed that a lack of communication was more difficult to manage than the wait itself. Parent's descriptions suggested this to be like a chasm with no knowledge of how to change the situation but to manage alone until such time contact is made by the service. By not providing adequate contact and information on waiting times, services are in danger of encouraging passivity by keeping parents dependant on the service. If made aware of the waiting time parents might be more inclined to use information given at a face to face appointment or search for their own answers and strategies. It may be therefore that parents who DNA have lost hope due to a lack of communication rather than a reduced willingness to attend an appointment (Robin, 1976).

Consequently, it is recommended that, even after a face to face appointment, services must ensure consistent communication is maintained periodically to keep parents informed of their progress in relation to their referral.



## **Clinical Practice in Relation to Counselling Psychology**

The therapeutic alliance is the essential tool which enables the client to remain in and comply with treatment (Bordin, 1979; Sexton & Whiston, 1994). A positive beginning is therefore important for the development of a quality therapeutic relationship. A negative waiting experience and unrealistic expectations can hinder, and in some cases, prevent a good client-therapist relationship from forming. The counselling psychologist therefore needs to be mindful of the experiences clients have encountered during the waiting period. Understanding the parents' experiences and expectations have informed the following recommendations:

5. It has already been highlighted that parents move along a continuum from passivity to activity, at the passive end of the spectrum parents appear to be predisposed towards a passive wait for a professional to provide 'the answer's'. Therefore the cycle shown in the model (see model fig. 1) could be eliminated by providing information of professional's clinical roles, responsibilities and realistic expectations phrased in a way to empower the parent and align them with the professional in relation to being the expert on their own child. This will also be useful in assisting the development of the client-therapist relationship and therefore add support to recommendation 6.

6. The parents' view of the professional was an important theme throughout the analysis. The idealistic notion of the professional has implications for parents' expectations of their first appointment. Parents who have waited a length of time for their child's first appointment and attend expecting to be given answers and a 'cure' may leave the service disillusioned; this may form the basis on which they decide not to return. Counselling psychologists therefore need to be clear at the point of

contracting what the process of therapy entails in relation to the theoretical application they are undertaking and encourage a collaborative style of being. It would seem reasonable for counselling psychologists to assess the parents' expectations and provide accurate information to carefully and respectfully disillusion parents whilst at the same time promoting the therapeutic alliance by fostering hope. Careful consideration of parental expectations needs to be sought if the counselling psychologist wants to promote a positive client-therapist relationship facilitating change through the clients existing resources (Hubble et al., 1999).

7. Given the position of counselling psychologists in relation to diagnosing (Pilgrim, 2000) we need to be aware of what having a diagnosis/answer means to the parent in terms of removing their self blame, parenting their child and eliciting external support such as professionals in the education system. If we do not provide a diagnosis we may need to explain why. Central to this process needs to be consideration of the parents hopes for a 'diagnosis', a working through of the failure to receive one and the implications of this for the child and family's needs.

### Limitations

A limitation of this research was the failure to use theoretical sampling which was in part due to the length of time it took to receive ethical approval and recruiting participants. The interviews were conducted, transcribed and analysed concurrently using a constant comparison method. This is a process of continually sifting and comparing data, merging categories and theoretical propositions (Pidgeon, 1998). This process enabled a full immersion in the data leading to a sensitivity to the emerging

categories and themes. However Strauss & Corbin (1998) argued that sampling and analysis must occur sequentially with analysis guiding data collection to avoid unevenly developed categories as theoretical sampling ensures the greatest theoretical return. Charmaz (1990) also purported that theoretical sampling, as in active sampling of new cases as the analysis proceeds, serves to extend or deepen the researcher's emergent understanding (Charmaz, 1990).

According to Pidgeon & Henwood (1998) the comparison method of analysis applied in the present research is adequate and given the almost identical experiences reported by all the parents could be argued as sufficient. However there were a few points that emerged from the interviews that could have informed a change of questioning in other interviews had the theoretical sampling method been applied. These were the parent's need to search for knowledge, the immense expectations of the professional and the powerful drive to receive a diagnosis. These points were mentioned by each parent, which highlighted a shared common experience and therefore arguably sufficiently analysed by the comparative method. However, there is a possibility that a deeper understanding of these concepts could have further developed and informed the categories if, after the first interview, the points had been included in the semi structured interview as required when applying theoretical sampling. For example, I may have gained a greater understanding of the underpinnings of the parent's expectations of the professional. This may have confirmed or refuted my hypothesis about unrealistic parental expectations, perpetuated by the recent increase of television programmes portraying psychologists as 'magicians'. Furthermore, I may have been able to establish the fundamental reasons for the strong drive for a diagnosis: was it to relieve the parent of guilt and responsibility as the data led me to believe or would I

have found an alternative reason such as the secondary reinforcer of Disability Living Allowances. Such considerations may have impacted my view of the parents active or passive stance and consequently would have had implications on the final model.

Future research would therefore need to consider incorporating the emerging points into the semi-structured interview and using the theoretical sampling method to ensure saturation and evenly developed categories.

Qualitative studies rely on detailed descriptive accounts of the phenomenon being researched and the theoretical formulations arising inductively from the material (McLeod, 2003); therefore apologies should never be given for the sample size (Parker, 1998). However the low response rate, that being 2.4% in the present research means that many views and voices were excluded that may perhaps have altered the findings and subsequent model. It would therefore be beneficial, both for service development and clinical application, for further research to be undertaken in this area to elaborate and explore the themes more thoroughly. One suggestion would be to use the present findings to begin a process of theoretical sampling, as discussed above, that would go further in securing a significant theoretical return.

Rawlinson & Williams (200) argued that unfulfilled appointments and un-productive clinician time serves to maintain long waiting lists. This research has investigated parents' experiences of waiting leading to their child's initial appointment. A further issue is the non attendance of subsequent appointments. This research has suggested that parents may attend an initial appointment with expectations on the professional providing an answer/diagnosis to elicit immediate relief from the difficulties they have encountered. Disillusionment due to unrealistic expectations may be the reason why

parents decide not to continue and consequently disengage. Understanding this phenomenon is as equally important as the present research for addressing long waiting times. For this reason further research is needed to fully understand what parent's experience in their initial engagement that might account for their disengagement to encourage a positive therapeutic outcome and inform service and clinical delivery.

In summary, despite the limitations, the research goes some way to understanding waiting lists from a potential service user's perspective for which no previous research has been identified. The aim of this research was to gain a rich understanding of how parent's experience and manage the waiting period to inform service delivery and elicit a positive therapeutic engagement. The interview data found that parents encounter both positive and negative experiences whilst waiting for their child's initial appointment. Their feelings of loneliness, abandonment and self blame lead to a position of either passivity or activity which is intensified by the corresponding dynamic as illustrated in fig. 1. An idealistic view of the professional, who is perceived as having the sought after answer/diagnosis, perpetuates the negative self state which sustains the passivity and weakens activity. Despite the level and intensity of experience all parent's interviewed stated their intention to attend their pending appointment regardless of the length of time waiting. This is contrary to existing literature in this field albeit limited (Jaffa & Griffin, 1990; Stern & Brown, 1994; Stallard & Potter, 1999; Rawlinson & Williams, 2000). Given the small sample size it is inappropriate to generalise the findings within and across services, however an understanding of how the parents perceived their experiences will encourage services to consider how parents might be supported during the waiting period. In doing so it is

anticipated that DNA rates will lessen and a positive therapeutic engagement be encouraged. Implications for service and clinical delivery have been discussed as well as the present research limitations and suggestions for further research.

### **Reflection**

The research experience I have experienced has been like a journey on a winding road. At times, the journey has been challenging and necessitated the utilisation of clinical and research supervision and personal therapy as support structures. However I feel the benefit has outweighed the cost in terms of my personal growth both clinically and academically and opened my eyes to new ways of thinking. During the research experience I at times felt I was engaged in a parallel process to the parent's experiences and could not fully relate to the model that had emerged from the data. I felt disempowered as I endured the long wait for ethical approval and can identify times when I actively engaged in literature searches and extending my knowledge in preparation thus paralleling parents search for knowledge. There were also times when I felt dispirited and became passive and drew on the support system around me.

King (1998) contended that the domain of the personal is a difficult and potentially emotionally disturbing area to unpack, but to deny our feelings and our constructions would be to shut out one large part of the research experience. Therefore an understanding of oneself as a researcher is a fundamental part of the qualitative researcher (West, 1998). The next section will give a brief critical account of the research process from a reflective and personal position that will give insight into what informed my choice of research and will illuminate further my own processes, how the

challenges were met, the difficulties I faced and how my findings add to the existing body of literature.

# **A CRITIQUE OF THE RESEARCH PROCESS AND REFLEXIVE PRACTICE**



### **My Choice of Research**

My initial research objective was born from my clinical experience of frustration when families failed to attend their appointment given my time allocated for preparation and assessment. In conjunction with my frustration was concern about the lengthening waiting list. I was surprised at the limited, out of date literature given the political climate regarding Child and Adolescent Mental Health Services (NHS Advisory Service, 1995) but was interested in the unanimous voice that poor attendance rates are closely associated with longer waiting lists (Stern & Brown, 1994; Kurtz, 1996; Stallard & Potter, 1999; Rawlinson & Williams, 2000). My primary aim at this point was to engage in a research process to establish why families decide not to attend and was therefore service development related. However following a particularly difficult assessment involving a family whose anger at having to wait so long had a negative impact upon the therapeutic engagement, I began to consider the clinical need to understand how the long wait for an appointment affected families, and the subsequent engagement with the clinician.

### **How the Challenges were Met**

In my original research design I intended to interview parents who had and had not attended their appointment to establish what had informed their decision. However on reflecting with my research supervisor I realised that answers to these questions could be superficial and that to gain real insight I needed to fully engage with parent's experiences of waiting to gain a deeper understanding to achieve my research aims.

My application to the first ethics board was accepted in its original form; however subsequent ethical boards requested changes and consequently the process took many months to complete. It was during this time I began to appreciate what it was like to feel myself at the mercy of a higher authority with something that was important in my life and necessary for my development. Although retrospectively I recognised that I was beginning a parallel process to the parents I would interview, as I too began the 'waiting game'. Alderfer (1985) contended that parallel processes occur within interpersonal interactions when one set of relationships mirror that of another system, in this case between myself and my participants. I found this to be true when, through the analytical process, as the themes began to emerge I realised the extent the themes applied to my own experience of waiting. I remained active during the waiting time by constantly updating my literature search using a variety of media. However there were times when I became disillusioned with the process and took a passive position. These were times when other situations were happening in my personal and professional life. During these times I felt helpless and disempowered knowing that I was unable to fight the system as I viewed the ethics panel as 'the experts' from whom I needed an answer. As I continued to wait, the way I viewed the ethics board professionals intensified the way I saw myself in terms of self doubt and lack of confidence. However the research was important to me as I wanted to make changes that would benefit the service and clients and therefore I never considered giving up. During times of passivity I drew on the strength and support of colleagues, friends and supervisors which helped to empower me to continue.

In the same way I was waiting to initiate change I reflected on the desired changes that the waiting list represented and felt an overwhelming sense of responsibility in terms

of what is expected from me as a counselling psychologist. I wanted immediate answers from the ethics boards to begin my process, but as a counselling psychologist whose professional training had been embedded in person-centred principles (Rogers, 1951) I considered whether I am able to fulfil the parents hopes of immediate answers to elicit immediate change? This led me to consider the therapeutic models that we impose on clients such as the psychodynamic counselling model (Messer et al., 1998) where change is slow and gradual because of its structural nature as compared with the cognitive behaviour model (Beck, 1995) which is more immediate resulting in a more observable change. I recognised the need to consider the holistic needs of the family in my assessment and not just the referring problem to inform my choice of intervention.

What I had not realised during my times of passivity was the growing resentment I experienced as I waited. This only became evident to me when permission was given for the research to begin and greatly influenced my initial motivation, which I worked through with my peers and supervisors. Seligman (1975) contended that aggression can be hidden in the form of passivity when frustrations cannot be changed due to perceived helplessness. I wondered whether I encourage families to share their true feelings at their initial assessments or whether their view of me as a professional prohibits this. I felt this awareness was important and needs to be considered during assessments to prevent passive aggressiveness disrupting the therapeutic process.

I entered the research process with a foremost desire to reduce the waiting list, which as a consequence would encourage a positive therapeutic beginning. However as the interviews began and I came alongside the parents in a bid to understand their

experiences my emphasis changed to needing to appreciate the experiences parents encounter with service development being the consequence. During the interviews I felt an overwhelming sense of helplessness as I sat with parents so desperate to get help for their child and knowing that as a counselling psychologist and a member of the Child and Family Service I had the expertise and skills to help. I realised that by engaging in the interview process my feelings of helplessness and frustration was the parent's transference and my countertransference connecting, continuing the parallel process (Sullivan, 2002). I found it difficult, but recognised the necessity to remain within the ethical boundaries of my role as a researcher. Knowing that I could not enter into a remit of formulating the presenting problem or offering intervention, my impulse was to return to the office and try and speed their appointments and listen for cancellations so that they could be seen sooner. I realised that by doing this I would be prolonging the wait for someone else that had been waiting possibly longer who may be in equal need. This led me to view the waiting list differently. Within the service and to the professionals the waiting list is as such – a waiting list, which contains names of children and young people waiting to be seen. During the interviews I began to appreciate that in real terms the waiting list is a list of hardship, heartache, sadness and devastation. As professionals we are in danger of forgetting there is a family behind the name on the waiting list as we become hardened through saturation, and immune to distress about which we can do very little (Stallard & Potter, 1999). How different would the service be, or how would we work differently if all the professionals appreciated the waiting list in different terms? Maybe the waiting list has become a protection from becoming overwhelmed and experiencing guilt and burnout for the professional. It is important to acknowledge the need to protect the

professional but equally there is a need to acknowledge what the waiting list has become to the family in terms of the experiences they encounter.

### **Difficulties I Faced**

The intensity and revelations together with my initial naivety within the first two interviews were what contributed to them being much shorter than the remaining four. The parents knew from my information sheet that I was part of the service and I therefore felt the need to boundary my role as a researcher away from that as a psychologist especially in view of my impulse to help relieve the stress the family were experiencing. However, Mearns & McLeod (1984) argued that qualitative research is similar to doing therapy in that the researcher uses empathy, genuineness and acceptance in developing relationships with informants. I therefore utilised my clinical supervision to work through my anxiety of blurring the boundaries in order to remain an effective researcher within my ethical limits. Using Rogers (1951) core conditions, in a sensitive and intuitive way as suggested by King (1998), in the subsequent interviews was undemanding, given my genuine interest and concern, and yielded comprehensive accounts of the parents' experiences which supported the finding of the previous shorter interviews. It was these first encountered interview difficulties and the time restraints caused, to some extent, by needing to wait for ethical approval that affected my ability to use theoretical sampling that would have given me a greater theoretical return (Strauss & Corbin, 1998). However, as Pidgeon (1998) contended, the comparison method of analysis I used is sufficient for subcategory development and identification of emergent themes following a full immersion of the data. The analysis was further validated through respondent validation (Henwood and Pidgeon, 1995).

As this was my first engagement with qualitative research I recognise that at times I was periodically overwhelmed by the time, dedication, intensity and vigour that was required throughout the analytical procedure. What I had naively thought to be a straight forward procedure following Pidgeon & Henwood's (1992) grounded theory principles turned into confusion and chaos as I continued through the process of line by line coding, recoding, converging and renaming categories, identifying links and emergent themes and creating a model from the findings. Close collaboration with my research supervisor was essential throughout this process.

### **The Contribution of this Research to the Existing Body of Literature**

The limited literature in the area of waiting lists and the focus on examining pre-defined hypothesis (Griffin, 1963; Raynes and Warren, 1971; Staver and LaForge, 1975; Lefebvre et al., 1983; Rawlinson & Williams, 2000) demonstrates an absence of theory in this area as no thought has previously been given to exploring the phenomenon with the people it most affected – the service user. Although my research did not directly address why parents choose not to attend, the findings relate to a rich understanding of their experiences which will enable services to consider their future developments in terms of supporting families during their waiting period or changing current practice to include brief face to face appointments as recommended in my previous section. The task of grounded theory is to discover new ways of making sense of social phenomenon and generate a formal theoretical framework for understanding phenomenon grounded in data (Pidgeon & Henwood, 1992). Grounded theory therefore has the potential to produce novel and wider theoretical perspectives where theory is otherwise missing or inadequate, which the present study epitomises.

Despite the present findings being conducive to a new theory there are parallels that can be drawn from the cognitive-behavioural paradigm. What has been themed as ‘active states’ and ‘passive states’ and their corresponding sub categories could also be attributed to ‘positive and negative automatic thoughts’ (Beck, 1995) with corresponding cognitive states. Building upon this future research would need to consider related cognitive theories to understand the dynamics between the ‘passive’ and ‘active’ state. Theoretical concepts such as motivation (McDougall, 1932) and self efficacy (Bandura, 1982) could provide insight to inform service developments and consequently support parents during the waiting period.

### **Conclusion**

The aim of this critical reflection was to personalise myself as the researcher to the reader to make explicit my personal and interpersonal qualities and consequently add insight and meaning to the research process. The difficulties and challenges I have faced and how they implicate the research have been discussed so that the reader can judge the research content in the context of the perspectives and assumptions by which it was shaped. In terms of service development, I began the research paper describing the length of waiting lists in the service where I work and the high DNA rate as a consequence. Following the outcome of this, research developments have already begun to change the existing system to a ‘face 2 face’ screening model where at present families are seen within six weeks of referral. We have already seen a reduction in missed appointments, which not only allows us to meet the needs of children, young people and their families in our area but has also served to increase the moral of the clinicians. From my own experience, engaging with families has been enhanced possibly due to the early ‘face 2 face’ appointment where appropriate

supporting information was provided, however further research will need to be undertaken with the new service model to establish if families feel more empowered, which became the heart of my endeavours.



## REFERENCES

Alderfer, C. P. (1985) Taking ourselves seriously as researchers. In D. N. Berg & K. K. Smith (Eds.) Exploring Clinical Methods for Social Research (pp. 35 – 70).

London: Sage.

Armstrong, P. W. (2000) First steps in analysing NHS waiting times avoiding the ‘stationary and closed’ population fallacy. Stat Med, 19, pp. 2037 – 2051.

Audit Commission (2001) Change Here: Managing Change to Improve Local Services. [www.audit-commission.gov.uk](http://www.audit-commission.gov.uk) accessed 27<sup>th</sup> June 2004.

Audit Commission (2002) The Performance of the NHS in England. [www.audit-commission.gov.uk](http://www.audit-commission.gov.uk) accessed 27<sup>th</sup> June 2004.

Audit Commission Survey (2003) Outpatients: Review of National Findings. [www.audit-commission.gov.uk](http://www.audit-commission.gov.uk) accessed 23<sup>rd</sup> March 2004.

Ball, S., Macrae, S. & Maguire, M. (1997) The post-16 education market. Paper presented at 6<sup>th</sup> Quasi-Market Research Seminar, Portsmouth, 10 – 11 April (cited by Hughes, D & Griffiths, L. (1999) On penalties and the Patient’s Charter: centralism v de-centralised Government in the NHS. Sociology of Health and Illness, vol. 21, no. 1, pp. 71-94).

Bandura, A. (1982) Self-efficacy mechanisms in human agency. American Psychologist, 37, pp. 122 – 147. Cited by Woolfe, R., Dryden, W. & Strawbridge, S. (2003) Handbook of Counselling Psychology (2<sup>nd</sup> Ed.) London: Sage Publications).

Beck, J. (1995) Cognitive Therapy: Basics and Beyond. New York: Guilford Press.

Bordin, E. S. (1979) The generalisability of the psychoanalytical concept of the working alliance. Psychotherapy: Theory, Research and Practice, 16, pp. 252-260.

Bowling, A. (1997) Research Methods in Health: Investigating Health and Health Studies. London: Open University Press

Buhler, C. (1971) Basic theoretical concepts of humanistic psychology. American Psychologist, 26, pp. 378-386.

Bulmer, M. (1979) Concepts in the analysis of qualitative data. In M. Bulmer (Ed.) Sociological Research Methods. London: Macmillan.

Burgoyne, R. W., Acosta, F.X., & Yamamoto, J. (1983) Telephone prompting to increase attendance at a psychiatric outpatient clinic. American Journal of Psychiatry, 140, pp.345-347.

Buss, A. R. (1978) The structure of psychological revolutions. Journal of the History of the Behavioural Sciences, 14, pp. 57-64.

Buttery, R. & Snaith, A. (1979) Waiting for surgery. British Medical Journal, 2, pp. 403-4.

Cambridge University Press (2006) [www.dictionary.cambridge.org/define](http://www.dictionary.cambridge.org/define)

Carpenter, P. J., Morrow, G. R., Del Gaudio, A. C., & Ritzler, B. A. (1981) Who keeps the first out-patient appointment? American Journal of Psychiatry, 138, pp.102-105.

Carvel, J. (2001) Hospital waiting times distorted. The Guardian, Thursday 1<sup>st</sup> February 2001. [www.guardian.co.uk/uk\\_news/story](http://www.guardian.co.uk/uk_news/story) accessed 24th March 2005.

Charmaz, C. (1990) Discovering chronic illness: using grounded theory, Social Science and Medicine, 30(11), pp. 1161-72.

Conservative Party press release 751/94, 1994). Conservative Party Archive [www.bodley.ox.ac.uk/dept/scwmss/cpa](http://www.bodley.ox.ac.uk/dept/scwmss/cpa)

Cooper, M. (1975) Rationing Health Care. London: Croom Helm. (Cited by Pope, C. (1991) Trouble in Store: some thoughts on the management of waiting lists. Sociology of Health and Illness 13:2, pp. 193-212).

Crisp, N. (2003) NHS Chief Executive, cited in Guardian newspaper Shifrin, T. (2003) NHS waiting times continue to drop, Guardian Newspaper, Wednesday, December 3<sup>rd</sup> 2003,\_(SocietyGuardian.co.uk), [www.guardian.co.uk/print/0%2C4811043-110418%2COO.html](http://www.guardian.co.uk/print/0%2C4811043-110418%2COO.html) accessed 24<sup>th</sup> March 2005

Crisp, N. (2005) Creating a patient-led NHS – delivering the NHS improvement plan,  
Department of Health 2005/4699

[www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicy](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicy)

accessed 30th July 2005.

Cullis, J. G. & Jones, P. E. (1983) Inpatient waiting: a discourse and policy proposal.

British Medical Journal, 287, pp. 1483-6.

Culyer, A. J. & Cullis, J. G. (1976) Some economics of hospital waiting lists in the

NHS. Journal of Social Policy, 5, pp. 239-64.

Denzin, N. K. & Lincoln, Y. S. (1994) Handbook of Qualitative Research eds.

London: Sage.

Department of Health (1991) The Patients Charter London: HMSO

Department of Health (1997) Provisional waiting list figures: 30 September 1997.

Press release 97/349. London: Department of Health.

[www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices](http://www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices)

Department of Health (1998) Extra £65 million to reduce NHS waiting lists – targeted  
cash boost to primary, community, mental health and social services. Monday 18<sup>th</sup>

May 1998. Department of Health Reference no. 98/190

[www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices](http://www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices) accessed

[22nd July 2005](#)

Department Of Health (1998) Rewards for Hitting Waiting List Targets – Frank Dobson – Patients to Gain from Extra Cash for Operations. Thursday 9<sup>th</sup> April 1998  
Department of Health Reference No. 98/139).

[www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices](http://www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices) accessed  
[22nd July 2005](#)

Department of Health (1998). Department of Health Reference no. 98/166

[www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices](http://www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices)  
accessed 22nd July 2005

Department of Health (2001) Further progress towards reducing waiting times,  
Department of Health Reference No. 2001/0529,

[www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices](http://www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices)  
accessed 22nd July 2005.

Department of Health (2003) Waiting lists stay below a million, Department of Health  
Reference No. 2003/0311

[www.dh.gov/PublicationsAndStatistics/PressRelease/PressReleaseNotices](http://www.dh.gov/PublicationsAndStatistics/PressRelease/PressReleaseNotices)  
accessed 30th July 2005.

Department of Health (2005) England summary - outpatient first attendances quarter 4  
(2004/2005), [www.performance.doh.gov.uk/waitingtimes2004/q4/qm08\\_y00](http://www.performance.doh.gov.uk/waitingtimes2004/q4/qm08_y00)  
accessed 30th July 2005.

Department of Health (2005) England summary - outpatient first attendances quarter 4 (2004/2005), [www.performance.doh.gov.uk/waitingtimes2004/q4/qm08\\_y00](http://www.performance.doh.gov.uk/waitingtimes2004/q4/qm08_y00) accessed 30th July 2005.

Department of Health dataset QMOP (2005) Government Statistical Service for the Department of Health, Gateway Reference ROCR/OR/0046/005, [www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsStatistics/PublicationsStatisticsArticle](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsStatistics/PublicationsStatisticsArticle). accessed 6th October 2006.

Department of Health, (1996) Hospital Waiting Lists England September 1996. Pubs & Stats: Publications [www.dh.gov.uk](http://www.dh.gov.uk).

Department of Health. (1994) Waiting times for first outpatient appointments in England: Quarter ended 31 December 1994. Statistical bulletin 1995/5. London: Department of Health.

Directgov, (2000) NHS Waiting List Figures Released. [www.pm.gov.uk/output/page964.asp](http://www.pm.gov.uk/output/page964.asp) accessed 24th March 2005.

Dixon, J (2005) Surgery carried out in car park. BBC News, Friday 18<sup>th</sup> March 2005, <http://news.bbc.co.uk/1/hi/England/London/4363005.stm> accessed 24th March 2005.

Doran, F. (1990) Increasing waiting lists. British Medical Journal, 300, pp.751.

Foreman, D. M. & Hanna, M. (2000) How long can a waiting list be? The impact of waiting time on intention to attend child and adolescent psychiatric clinics. Psychiatric Bulletin, 24, pp.211-213.

Frankel S. The natural history of waiting lists: some wider explanations for an unnecessary problem. Health Trends, 21, pp. 54-56.

Freud, S. (1927) The future of an illusion. In Vol. XXII of The Standard edition. London: Hogarth, 1961. (Cited by Monte, C. F. (1999) Behind the Mask: An Introduction to Theories of Personality (6<sup>th</sup> Ed.) Orlando: Harcourt Brace College Publishers).

Frost, C. E. B. (1980) How permanent are NHS waiting lists? Social Science and Medicine, 14c, pp. 1-11.

Gergen, K. J. (1985) The social constructionist movement in modern psychology. American Psychologist, 40, pp. 266 – 275.

Glaser, B.G. and Strauss, A.L. (1967) The Discovery of Grounded Theory: Strategies for qualitative research. New York: Aldine.

Griffin, M. (1963) The Effects of Waiting Lists on Patients and Staff. Chicago: Illinois Department of Mental Health.

Hamblin, R., Harrison, A. and Boyle, S. (1998) The wrong target. Health Service Journal, 2 April pp. 28-31

Health Minister John Hutton (2001) cited in Department of Health (2001) Further progress towards reducing waiting times, Department of Health Reference No. 2001/0529,

[www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices](http://www.dh.gov.uk/PublicationsAndStatistics/PressRelease/PressReleaseNotices) accessed 22nd July 2005.

Healthcare Commission (2003) Outpatient survey.

[www.healthcarecommission.org.uk/PatientSurveyOutpatients2003](http://www.healthcarecommission.org.uk/PatientSurveyOutpatients2003)

accessed 5<sup>th</sup> July 2005.

Healthcare Commission (2005) Patient survey programme 2004/2005.

[www.healthcarecommission.org.uk/PatientSurveyOutpatients2005](http://www.healthcarecommission.org.uk/PatientSurveyOutpatients2005)

accessed 5<sup>th</sup> July 2005.

Hemingway, H. & Jacobson, B. (1995) Queues for cure? British Medical Journal, April, 310, pp. 818 – 819.

Henwood, K. L. & Pidgeon, N. F. (1995) Remaking the link: Qualitative research and feminist standpoint theory, Feminism & Psychology, 5(1), pp.7-30.

Henwood, K. L. & Pidgeon, N. F. (1992) Qualitative research and psychological theorising, British Journal of Psychology, 83, pp. 97-111.



Hochstadt, N.J. & Trybula, J. (1980) Reducing missed initial appointments in a community mental health centre. Journal of Community Psychology, 8, pp.261-265.

Holosko, M.J., Leslie, D.R & Cassano, D.R (2001) How service users become empowered in human service organisations: the empowerment model. International Journal of Health Care Quality Assurance 14/3 pp. 126-132.

Houghton, P. W. J. & Brodribb, A. J. M. (1989) Failure to attend for operation: a comparison between booked admissions and the waiting list system. British Medical Journal, 299, pp. 1139-40. (cited by Pope, C. (1991) Trouble in Store: some thoughts on the management of waiting lists. Sociology of Health and Illness 13:2, pp. 193-212).

House of Commons Health Committee (1994)

[www.publications.parliament.uk/pa/cm200304](http://www.publications.parliament.uk/pa/cm200304) in Radical Statistics Health Group (1995) NHS “indicators of success”: what do they tell us? British Medical Journal, 310, pp 1045-1050.

Hubble, M. A., Duncan, B. L.. & Miller, S. D. (eds.) (1999) The Heart and Soul of Change: What Works in Therapy. Washington DC: American Psychological Association (cited by Woolfe, R., Dryden, W. & Strawbridge, S. (2003) Handbook of Counselling Psychology (2<sup>nd</sup> Ed.) London: Sage Publications.

Hughes, D & Griffiths, L. (1999) On penalties and the Patient's Charter: centralism v de-centralised Government in the NHS. Sociology of Health and Illness, vol. 21, no. 1, pp. 71-94.

J Lloyd, D Dillon and K Hariharan (2003) Down the line Health Service Journal, 113, January 9<sup>th</sup> p.22-23.

Jaffa, T. & Griffin, S. (1990) Does a shorter wait for a first appointment improve the attendance rate in child psychiatry? Associated Child Psychology Psychiatric Review Newsletter, 12, pp. 9-11.

Jessop, J. (1989) Let's play pass the patient, Health Service Journal, 99, pp. 957. (cited by Pope, C. (1991) Trouble in Store: some thoughts on the management of waiting lists. Sociology of Health and Illness 13:2, pp. 193-212).

Jones, E., Lucey, C., & Wadland, L. (2000) Triage: A waiting list initiative in a child mental health service. Psychiatric Bulletin, 24, pp.57-59.

King, E. (1998) The use of the self in qualitative research. In J. T. E. Richardson (Eds.) Handbook of Qualitative Research Methods. Leicester: British Psychological Society.

Kluger, M.P. & Karras, A. (1983) Strategies for reducing missed initial appointments in a community mental health centre. Community Mental Health Journal, 19(2), pp.137-143.

Kurtz, Z. (1996) Treating Children Well. A Guide to Using the Evidence Base in Commissioning and Managing Services for the Mental Health of Children and Young People. London: Mental Health Foundation. (cited by Stallard, P. & Potter, R. (1999) Making sense of Child and Adolescent Mental Health Service. Psychiatric Bulletin, 23, pp217-221).

Lazarus, R. S. (1976) Patterns of Adjustment. New York: McGraw-Hill (cited by Woolfe, R., Dryden, W. & Strawbridge, S. (2003) Handbook of Counselling Psychology (2<sup>nd</sup> Ed.) London: Sage Publications.

Lazarus, R.S. & Folkman, R. (1984) Stress, Appraisal and Coping. New York: Springer (cited by Woolfe, R., Dryden, W. & Strawbridge, S. (2003) Handbook of Counselling Psychology (2<sup>nd</sup> Ed.) London: Sage Publications.

Lefebvre, A., Sommerauer, J., Cohen, N., Waldron, S. & Perry, I. (1983) 'Where did all the no-shows go?' Canadian Journal of Psychiatry, vol. 28, pp. 387-390.

Leff, S. & Bennett, J. (1998) Developing guidelines for community child health staff and examining the referral pathways and outcomes of care in the support of emotionally and behaviourally disturbed children. Public Health, 112, pp. 237-241.

McDougall, W. (1932) The Energies of Men. London: Methuen. Cited by The Foundations of Psychology: An Introductory Text. London: Routledge,

Maslow, A.H. (1970) Motivation and Personality (2<sup>nd</sup> ed.) New York: Harper & Row

Mathai, M. & Markantonakis, A. (1990) Improving initial attendance to a child and family psychiatric clinic. Psychiatric Bulletin, 14, pp. 151-152.

May, R. (2001) Crossing the them and us barriers: an inside perspective on user involvement in clinical psychology. Clinical Psychology Forum (2001) No 150 April. pp14-18.

McLeod, J. (2001) Qualitative Research in Counselling and Psychotherapy. London: Sage Publications

McLeod, J. (2003) Qualitative research methods in counselling psychology . In Handbook of Counselling Psychology 2<sup>nd</sup> Edition. London: Sage Publications.

Mearns, D. & McLeod, J. (1984) A person-centred approach to research. In R. Levant & J. Shlien (Eds.) Client Centred Therapy and the Person-Centred Approach: New Directions in Theory, Research and Practice. New York: Praeger.

Mearns, D. & Thorne, B. (2001) Person-centred Therapy Today: New Frontiers in Theory and Practice. London: Sage Publications.

Messer, S. B., Sass, L. A. & Woolfolk, R. L. (Eds.) (1988) Hermeneutics and Psychological Theory: Interpretive Perspectives on Personality, Psychotherapy and Psychopathology. New Brunswick NJ: Rutgers University Press (cited by McLeod, J. (2003) Qualitative research methods in counselling psychology. In Handbook of Counselling Psychology 2<sup>nd</sup> Edition. London: Sage Publications.

Monte, C. F. (1999) Behind the Mask: An Introduction to Theories of Personality (6<sup>th</sup> Ed.) Orlando: Harcourt Brace College Publishers.

National Health Service Improvement Plan (2004) Putting People at the Heart of Public Services The Stationary Office.

[www.dh.gov.uk/assetRoot/04/08/45/22/04084522.pdf](http://www.dh.gov.uk/assetRoot/04/08/45/22/04084522.pdf) accessed 24<sup>th</sup> November 2005.

National Health Service Management Executive (1993) cited by Hemingway, H. & Jacobson, B. (1995) Queues for cure? British Medical Journal, April, 310, pp. 818 – 819.

National Health Service Modernisation Agency (2003) Primary targeting lists: towards a fully booked NHS. [www.modern.nhs.uk/access](http://www.modern.nhs.uk/access) accessed 5th July 2005.

National Health Service Plan (2000) Department of Health NHS Plan: A Plan for Investment: A Plan for Reform. The Stationary Office.

Newton, J. N., Henderson, J. & Goldacre, M. J. (1995) Waiting list dynamics and the impact of earmarked funding. British Medical Journal, Sept vol.311, pp. 783 - 785

NHS Advisory Service (1995) Child and Adolescent Mental Health Services: Together We Stand. London: HMSO. (cited by Stallard, P. and Potter, R. (1999) Making sense of child and adolescent mental health service. Psychiatric Bulletin, 23, pp217-221).

NHS Advisory Service (1995) Child and Adolescent Mental Health Services: Together We Stand. London: HMSO. (cited by Stallard, P. and Potter, R. (1999) Making sense of child and adolescent mental health service. Psychiatric Bulletin, 23, pp217-221).

Oakeshott, I. & Beattie, J. (2005) Evening Standard: This is London.

[www.thisislondon.co.uk/news/articles/17343975](http://www.thisislondon.co.uk/news/articles/17343975) accessed 18th August 2005.

Palmer, S. (2003) Stress management and prevention programmes. In Woolfe, R.,

Dryden, W. & Strawbridge, S. (2003) Handbook of Counselling Psychology 2<sup>nd</sup> Ed.

London: Sage.

Parker, I. (1992) Discourse Dynamics: Critical Analysis for Social and Individual Psychology. London: Routledge.

Parker, I. (1998) Qualitative Research. In Banister, P., Burman, E., Parker, I., Taylor,

M & Tindall, C. (Eds.) Qualitative Methods in Psychology: A Research Guide.

Buckingham: Open University Press.

Parker, K. C. & Froese, A. P. (1992) Waiting list information strategies for child

psychiatry: an intervention and measurement approach. Canadian Journal of

Psychiatry, 37, pp. 387 – 392.

Pidgeon, N. & Henwood, K. (1992) Using grounded theory in psychological research.

In Hayes, N. (1998) Doing Qualitative Analysis in Psychology eds. Sussex:

Psychology Press Ltd., Publishers.

Pidgeon, N. & Henwood, K. (1998) Grounded theory: practical implementation. In

Richardson, J. T. E. (1998) Handbook of Qualitative Research Methods (Eds.).

Leicester: British Psychological Society.

Pidgeon, N. (1998) Grounded theory: theoretical background. In J. T. E. Richardson

(Eds.) Handbook of Qualitative Research Methods. Leicester: British Psychological

Society.

Pilgrim, D. & Waldron, L. (1998) User involvement in mental health service

development; How far can it go? Journal of Mental Health (7)1 pp 95-104.

Pilgrim, D. (2000) Psychiatric Diagnosis: more questions than answers. Psychologist,

13 (6): pp. 302-5.

Plante, G & Meloche, M (1977) L'intake et la liste d'attente. Canadian Psychiatric

Association Journal, 22, pp. 57-65. (cited by Jaffa, T. and Griffin, S. (1990) Does a

shorter wait for a first appointment improve the attendance rate in child psychiatry?

Associated Child Psychology Psychiatric Review Newsletter, 12, pp. 9-11.

Pope, C. (1991) Trouble in Store: some thoughts on the management of waiting lists.

Sociology of Health and Illness 13:2, pp. 193-212.

Pope, V. & Sykes, P. A. (2003) The forgotten wait: official waiting times often

misleading. Clinical Governance: an International Journal, vol. 8, no. 2, pp. 108 – 111.

Radical Statistics Health Group (1995) NHS “indicators of success”: what do they tell us? British Medical Journal, 310, pp 1045-1050.

Rawlinson, S. & Williams, R. (2000) The primary/secondary care interface in child and adolescent mental health services: the relevance of burden. Current Opinion in Psychiatry, vol. 13(4), pp. 389-395.

Raynes, A.E. & Warren, M.S. (1971) Some distinguishing features of patients failing to attend a psychiatric clinic after referral. American Journal of Orthopsychiatry, 41: pp. 581-8. (cited by Lefebvre, A., Sommerauer, J., Cohen, N., Waldron, S. and Perry, I. (1983) ‘Where did all the no-shows go?’ Canadian Journal of Psychiatry, vol. 28, pp. 387-390).

Raynes, A.E. & Warren, M.S. (1971) Some distinguishing features of patients failing to attend a psychiatric clinic after referral. American Journal of Orthopsychiatry, 41: pp. 581-8. (cited by Lefebvre, A., Sommerauer, J., Cohen, N., Waldron, S. and Perry, I. (1983) ‘Where did all the no-shows go?’ Canadian Journal of Psychiatry, vol. 28, pp. 387-390).

Reber, A. S. (1985) Penguin Dictionary of Psychology. Hammondsworth: Penguin.

Robin, A, (1976) Rationing out-patients: a defence of the waiting list. British Journal of Psychiatry, 128, pp. 138-41.

Rogers, C. (1951) Client Centred Therapy. London: Constable.



Roland, M. & Morris, R. (1988) Are referrals by general practitioners influenced by the availability of Consultants? British Medical Journal, 297, pp. 599-600.

Rotter, J. B. (1966) Generalised expectancies for internal versus external control of reinforcement. Psychological Monographs: General and Applied, 80, pp. 1-26 (cited by Woolfe, R., Dryden, W. & Strawbridge, S. (2003) Handbook of Counselling Psychology (2<sup>nd</sup> Ed.) London: Sage Publications.

Segal, L. (1986) The Dream of Reality: Heinz Von Foerster's Constructivism. New York: Norton. (cited by Pigeon, N. & Henwood, K. (1992) Using grounded theory in psychological research. In Hayes, N. (1998) Doing Qualitative Analysis in Psychology eds. Sussex: Psychology Press Ltd., Publishers).

Seligman, M. E. P. (1975) Helplessness: On Depression, Development and Death. San Francisco: W. H. Freeman (cited by Hayes, N. (1994) Foundations of Psychology: An Introductory Text. London: Routledge.

Sexton, T. L. & Whiston, S. C. (1994) The status of the counselling relationship: an empirical review, theoretical implications and research directions. Counselling Psychologist, 22, pp. pp.6 – 78.

Shaw, V. (2005) New waiting lists fury...but now hospitals are under fire for seeing patients too quickly. Leeds Today Evening Post, 18<sup>th</sup> March 2005,  
[www.leadstoday.net/ViewArticle2.aspx?SectionID=39&ArticleID=976208](http://www.leadstoday.net/ViewArticle2.aspx?SectionID=39&ArticleID=976208)  
accessed 25<sup>th</sup> March 2005.

Shifrin, T (2004) NHS waiting times 'getting shorter' Guardian Unlimited, Friday May 7<sup>th</sup> 2004, ([SocietyGuardian.co.uk](http://SocietyGuardian.co.uk)).

Shifrin, T. (2003) NHS waiting times continue to drop, Guardian Newspaper, Wednesday, December 3<sup>rd</sup> 2003, ([SocietyGuardian.co.uk](http://SocietyGuardian.co.uk)),  
[www.guardian.co.uk/print/0%2C4811043-110418%2COO.html](http://www.guardian.co.uk/print/0%2C4811043-110418%2COO.html)  
accessed 24<sup>th</sup> March 2005.

Sky News (2005) Labour's health pledge, Sky News, 8<sup>th</sup> March 2005,  
[www.sky.com/skynews/article/0,,30100-13307363,00.html](http://www.sky.com/skynews/article/0,,30100-13307363,00.html) accessed 24<sup>th</sup> March 2005.

Sky News, (2004) NHS waiting lists down, Sky News, Friday December 3<sup>rd</sup> 2004,  
[www.sky.com/skynews/article/0,,30100-13260452,00.html](http://www.sky.com/skynews/article/0,,30100-13260452,00.html) accessed 24<sup>th</sup> March 2005.

Stallard, P. & Potter, R. (1999) Making sense of child and adolescent mental health service. Psychiatric Bulletin, 23, pp217-221.

Staver, N. & LaForge, E. (1975) Intake as a conflict area in clinic function. Journal of American Academic Child Psychiatry, 14, pp. 589-99.

Stern, G. & Brown, R. (1994) The effect of a waiting list on attendance at initial appointments in a child and family clinic. Child: Care, Health and Development, 20, pp. 219-230.

Stratton, P. (1992) Selling constructionism to market research. Human Systems, 3, pp. 253-273. (cited by Pigeon, N. & Henwood, K. (1992) Using grounded theory in psychological research. In Hayes, N. (1998) Doing Qualitative Analysis in Psychology eds. Sussex: Psychology Press Ltd., Publishers).

Strauss, A. & Corbin, J. (1990) Basics of Qualitative Research: Grounded Theory Procedures and Techniques. London: Sage.

Strauss, A. & Corbin, J. (1998) Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory, 2<sup>nd</sup> edition. Thousand Oaks CA: Sage.

Strawbridge, S. & Woolfe, R. (2003) Counselling psychology in context. In Handbook of Counselling Psychology 2<sup>nd</sup> Edition. London: Sage Publications.

Sullivan, C. C. (2002) Finding the thou in the I: Countertransference and parallel process analysis in organisational research and consultation. The Journal of Applied Behavioural Science, vol. 38, no. 3, pp. 375 – 392.

Todd, J. W. (1984) Referrals to hospital, The Lancet, ii, p.1089.

Tudor Edwards, R. (1997) NHS Waiting Lists: Towards the Elusive Solution. Office for Health Economics: London.

Watson, J. B. (1913) Psychology as the behaviourist views it. *Psychological Review*, 20, pp. 158-177 (Cited by Monte, C. F. (1999) Behind the Mask: An Introduction to Theories of Personality (6<sup>th</sup> Ed.) Orlando: Harcourt Brace College Publishers).

Wennberg, J. E., Barnes, B. A. & Zubkoff, M. (1982) Professional uncertainty and the problem of supplier induced demand, *Social Science and Medicine*, 16, pp. 811-24.

Wenning, K. & King, S. (1995) Parent orientation meetings to improve attendance and access at a child psychiatric clinic. *Psychiatric Services*, 46, pp. 831-833.

West, L. (1994) Whose story, whose terms? Some problems of reflectivity in life history research. In *Life Histories and Learning: Language, the Self and Education*. Falmer: Centre for Continuing Education. University of Sussex and Canterbury: School of Continuing Education, University of Kent. (cited by Richardson, J. T. E. (1998) (Eds.) *Handbook of Qualitative Research Methods*. Leicester: British Psychological Society).

What do Words Mean (2206) [www.whatdowordsmean.com](http://www.whatdowordsmean.com)

Woolfe, R. (1990) Counselling psychology in Britain: an idea whose time has come . In *Handbook of Counselling Psychology 2<sup>nd</sup> Edition*. London: Sage Publications.

Wordnet (2003) [www.wordnet.princeton.edu](http://www.wordnet.princeton.edu)

[www.society.guardian.co.uk/nhsperformance/story/0%2C8150%2C1211660%2C00](http://www.society.guardian.co.uk/nhsperformance/story/0%2C8150%2C1211660%2C00)

accessed 24<sup>th</sup> March 2005.

Yin, R. (1994) Case Study Research: Design and Methods, 2<sup>nd</sup> ed. Thousand Oaks.  
California: Sage.

## APPENDICES

# **APPENDIX I**

The Framework of a Four Tier Service

## The framework of a four tier service put into place by the NHS advisory (1995)

### Tier one

Practitioners at tier one would routinely

- ❖ Provide information to parents about common emotional and behavioural problems
- ❖ Provide basic advice when parents initially present with a single issue problem
- ❖ Pick up early stages of severe disturbances, such as autism, severe emotional abuse, emotional deprivation, eating disorders etc.
- ❖ Look to initiate and maintain developments that support children and adolescents with emotional or behavioural problems
- ❖ Pick up early signs which may indicate possible damage to mental well-being.

### Tier two

Practitioners at tier two would provide

- ❖ Assessment of child and family, concentrating on the quality of relationships. In addition consider the current pressures, stresses, and strength within which the child and family co-exist.
- ❖ Developing treatment and/or interventions based on assessment taking into account current research regarding efficacy. Interventions may include individual work with child, work with parents – family orientated, parent groups and parent training.
- ❖ Joint work – liaison between other agencies.
- ❖ Movement between tier two and tier three. This may involve bringing in another specialist worker to provide multi-level interventions with children and families.

### Tier three

Practitioners at tier three would routinely provide

- ❖ A comprehensive assessment that would include social, medical, psychological, cognitive, genetic and developmental components. A broad view of a child and his/her family would be used to gain a full understanding of their difficulties.
- ❖ A clear and specific intervention plan normally involving multi-level input with children and family. Intervention is usually weekly and for longer than six months. The primary focus is to provide high quality specialist multi-level interventions that try to maintain the child within his/her community.
- ❖ Liaise with other agencies at a management as well as case level in order to provide a co-ordinated package of care.
- ❖ Refer on to tier four where there is likely to be early onset of psychosis, severe anorexia, severe hyperactivity, severe and prolonged soiling, severe psychosis, severe eating disorder, severe neuro psychiatric problems.



- ❖ An emergency service for young people who harm themselves or are at risk of harming themselves. This includes assessing the child/adolescent, following them up as necessary and liaising with community and paediatric services.

Tier four

Tier four service would involve

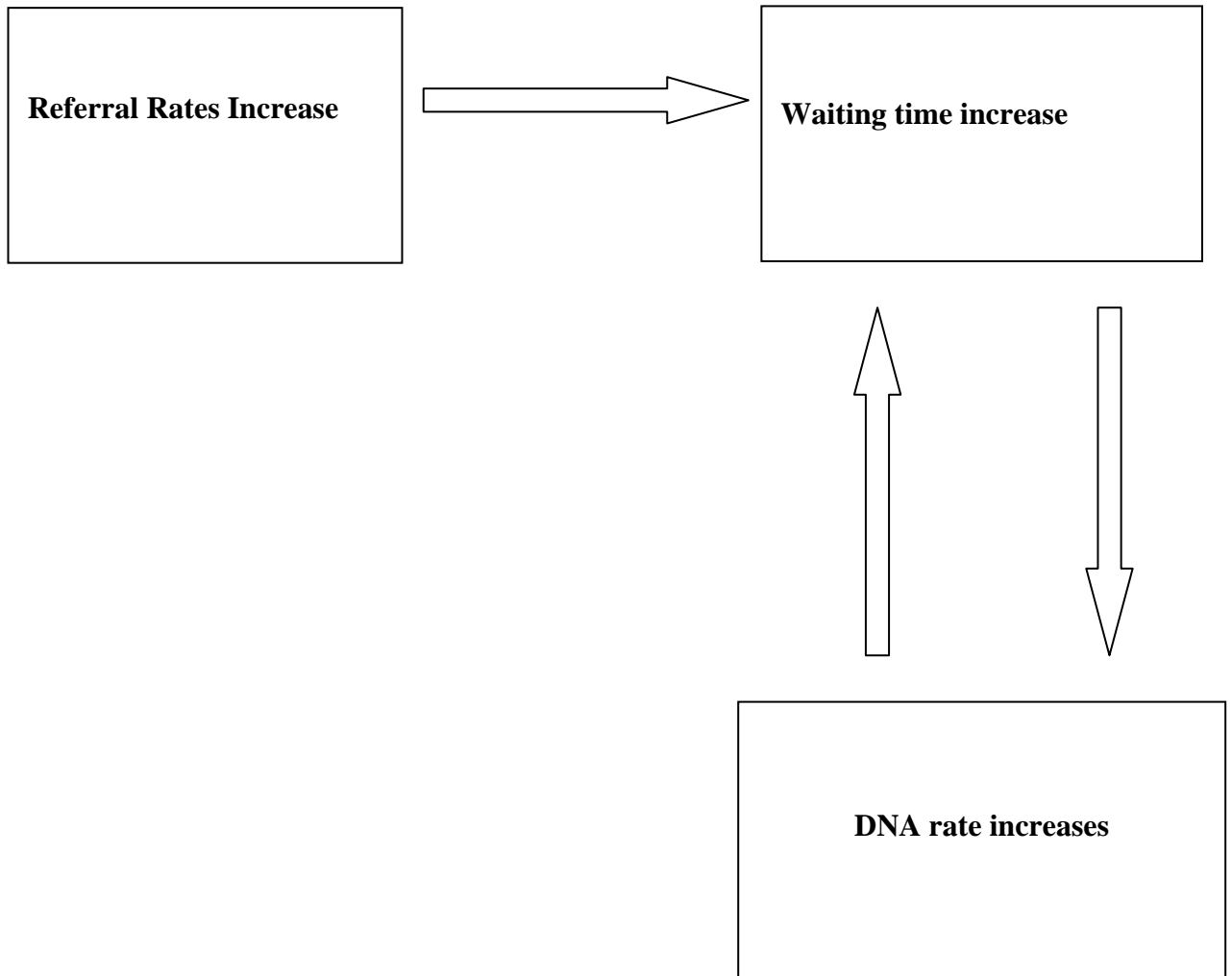
- ❖ Hospitalisation
- ❖ Residential care

## **APPENDIX II**

The Relationship Between Referral Rates, Waiting Times and DNA

Rawlinson and Williams (2000).

The relationship between referral rates, waiting times and DNA (failure to attend) rates. Rawlinson and Williams (2000).



## **APPENDIX III**

Example of Semi-Structured Interview Questions

## Semi-Structured Interview Questions

- 1. Can you describe any positive experiences you have had while being on the waiting list, commenting on what made the experience positive for you.**  
*(For example: Did you learn anything about yourself and family during this time? Did your problem resolve itself? Did you find self-help groups/own resources instead? Did it give you time to think?)*
- 2. Try to describe any negative experiences you have had while being on the waiting list, commenting on what made the experience negative for you.**  
*(For example: Did the problem worsen in any way? Did your feelings about attending an appointment alter – did you go off the idea?)*
- 3. Please describe any significant events or major turning points whilst on the waiting list, which resulted in a change to your experience.** *(For example: Did anyone leave or join the family? Did anyone else offer help? Did anyone develop a serious illness?)*
- 4. Please comment on what made these events significant for you.** *(For example: Did they make the problem better? Did they make the problem worse?)*
5. What aspects of being on the waiting list have you found most unhelpful?
6. What aspects of being on the waiting list have you found potentially helpful?

## **APPENDIX IV**

Example of Information Sheet

Child and Family Service  
Penn Fields Health Centre  
Upper Zoar Street  
Wolverhampton  
WV3 OJH

Tel: 01902 444021

Fax: 01902 444780

<http://www.wolverhamptonhealth.nhs.uk/>

DATE:

ADDRESS:

Dear Parent/Carer

**An Investigation into the Waiting List Experience – Exploring Parents Views of Children Referred to a Child and Adolescent Mental Health Service.**

I am a Counselling Psychologist undertaking the above research under the supervision of the University of Wolverhampton for the Child and Family Service in Wolverhampton. You are being invited to take part in the research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me on the above number if you would like any further information. Thank you for reading this.

What is the purpose of the study?

The research is designed to investigate parent experiences of being on a waiting list following a referral for their son/daughter to the Child and Family Service, Wolverhampton, by their GP.

Why have I been chosen?

As you are currently on a waiting list your thoughts and feelings are important and necessary for improvements to the process to be made. Therefore your willingness to participate in the research would be gratefully received.

What would happen if I took part?

The format will be a 45-minute interview in which your experiences, thoughts and feelings will be respectfully heard. If you agree to take part I will contact you and invite you to attend an interview appointment at Pennfields Health Centre, the address on top of this letter, at a convenient time for you. Travel expenses occurred will be refunded. The interview will be tape-recorded and you will be asked to sign a consent form allowing the researcher to use the material.

It is important to understand that your participation in the interview is for research purposes only and will not in any way be a therapeutic visit. Participation will not affect your place on the waiting list; neither will it result in shortening your waiting time. However, as a service user the contribution of your waiting experience will enable us to improve the existing service.

Will my taking part in this study be kept confidential?

Some of the material may be published, however, your confidentiality will be guarded and you will not be identifiable. The tape recordings will be kept in a locked cabinet and will only be identified through a number known to the researcher. Following transcription the tapes will be destroyed and after the research is complete any papers will be shredded. As a member of the British Psychological Society I am bound to working in accordance with the Society's guidelines and code of ethics. Copies of the guidelines are available on request.

Do I have to take part?

You are under no obligation to take part in this research. If you decide to take part you will be given this information letter to keep and asked to sign a consent form. You will also have the right to withdraw from the research at anytime without any consequences. Nothing you say or do during the research will affect the standard of care your child may receive in the future.

If you decide to take part you will be notified on completion of the research the outcome and how it will be used to improve the Child and Family Service in the future.

If you are willing to take part please return the confirmation slip enclosed in the stamped addressed envelope provided. On receipt of the confirmation I will contact you to arrange an appointment suitable to yourself for the interview to take place.

Yours faithfully,

Wendy Woodhouse  
Counselling Psychologist in Training/Researcher  
**CHILD AND FAMILY SERVICE**



## **APPENDIX V**

Example of Reply Slip

Child and Family Service  
Penn Fields Health Centre  
Upper Zoar Street  
Wolverhampton  
WV3 OJH

Tel: 01902 444021

Fax: 01902 444780

<http://www.wolverhamptonhealth.nhs.uk/>

**Title of Research**

An Investigation Into the Waiting List Experience – Exploring Parents Views of Children Referred to a Child and Adolescent Mental Health Service

**Researcher**

Wendy Woodhouse

**Contact Number**

Child and Family Service 01902 444021

I would like to take part in the research named above. I understand that my involvement will be kept confidential and I am free to withdraw at anytime. I also understand that if I decide to withdraw, the standard of care my child may receive will not be affected.

I agree to the researcher contacting me on the above number to arrange an interview date convenient to myself.

Signed .....

Name .....

Address.....

.....

.....

Telephone Number

## **APPENDIX VI**

Example of Consent Form

**PLEASE READ THIS LETTER CAREFULLY**

**PLEASE ASK IF THERE IS ANYTHING YOU DO NOT UNDERSTAND OR WOULD LIKE MORE INFORMATION ABOUT**

**Title of Research** An Investigation into the Waiting List Experience – Exploring Parents Views of Children Referred to a Child and Adolescent Mental Health Service.

**Researcher** Wendy Woodhouse

I ..... hereby give consent to participate in the above research investigation. The aim of the research and my involvement has been fully explained to me and my consent is freely given.

I understand that any information that I give will be treated respectfully and confidentially. I also understand that the interview will be tape-recorded. I am aware that should I decide to take part I am still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care my child may receive in the future.

I also understand that I will not be identifiable in any way in written or published reports of the research investigation and that on completion of the research I will be informed of the findings and how they will be used to improve the Child and Family Service.

I have been made aware that the researcher works in accordance to the British Psychological Society’s guidelines and code of ethics and have been informed that a copy is available on request.

Signed ..... Date .....  
Parent/Carer

Witness ..... Date ..... Researcher  
\*\*\*\*\*

## **APPENDIX VII**

Example of Transcript Analysis Line by Line Coding, Formation of Sub Categories and Central Relationships.

<b>Transcript (Taken from Interview 5)</b>	<b>Line by Line Coding</b>	<b>Formation of sub- categories</b>	<b>Central Relationships (Linking)</b>
<b>I</b> Well the closer you are to be seen the more upbeat you are so the more sort of relaxed I suppose to certain elements of the problems and so yes, yes I suppose because you are more getting used to how you deal with then and its 'oh! There is light at the end of the tunnel, we are nearly there, we are nearly there'. So it kind of... it does get easier.	Hope in Professional	Expectations of professional	how the professional is viewed reinforces parent negative self state
<b>R</b> Can you describe any negative experiences you have had... that you are having while you are waiting?	Knowledge of appointment intervention itself	Positive waiting experience	Knowledge increases empowerment
<b>I</b> Just the time waiting really. You just want to find the answer. You just want to know is it just me? Am I a bad mother? Is there something wrong with my child? Or is there something more? So that's really sort of the negatives I think it's the not knowing and the keep hearing 'oh well there is a waiting list... you have to wait your turn'. Yes well we know that but is there some sort of way you can just yes or no. I know at the end of the day it isn't as easy as that it has to take time but it's just nice to be told well actually there might be something or well no there is not or when it might be.	Feeling in control – anticipation professional will have answers	Professional as expert	Belief in professional as expert reinforces desire for diagnosis and ensures attendance – also reinforces negative self state
	Negative – not knowing	Negative waiting experience	Negative experience intensifies passivity
	Blame self – bad mother	Disempowered Self blame	Self blame can lead to a position of loneliness and a negative self view. May lead to feelings of helplessness and disempowerment resulting in need for containment – continues cycle of passivity
	Want to know	Need for containment	
	Not knowing	Helplessness	
	Power of waiting list – helpless		
	Need for knowledge	Lack of knowledge	Lack of knowledge perpetuates disempowerment and passivity
	Need to feel contained and in control	Need for containment	Need for containment leads to continued state of passivity

## **APPENDIX VIII**

Example of Building Subcategories

Example of building subcategories “self as alone” and “self as abandoned” informing the theme “States of Self”.

**Self as Alone**

They don't see the inside they don't see what we have at home, what goes on when the door is shut (Interview 3: line 364-377).

It's alright for some professionals they come and do fantastic jobs but then they go home at 5pm, we don't (Interview 3: line 941-946).

Now to find that I have nobody up here that I could that for, to have to do it all for myself, I mean in the end now I do 90% of my shopping on the internet so that I don't have to take her around the shops to make her anymore upset than she need be (Interview 4: line 253-261).

Gutting... it's really upsetting because you think I am no nearer than I was 3 weeks ago although you expect it because no miracle is going to come there is a list and you do have to wait your turn but its just sort of... please help somebody!!! (Interview 5: line 667-676).

Even me Doctor you know and other health visitor.... I used to speak to them and all I would get is 'I understand' and you know I used to think... well no you don't you can't because you haven't got a child like mine (Interview 6: line 614-622).

**Self as Abandoned**

It feels as if really you have just been forgotten... if .... well they say my name is on the list but they.... they're coming to us but nobody has mentioned it since. The GP has just said 'oh you can go on the waiting list' and that's about it (Interview 2: line 183-190).

As soon as they referred me there has been nothing. It has literally felt like we have been 'dumped'. There has been no letter to say that I was now on the waiting list for Child and Family Service (Interview 3: line 67-72).

We have been left dangling from one thing to another so we have had so many months where – well I don't know what to do shall I phone them shall I not (Interview 3: line 194-200).

Your sitting there panicking thinking 'well maybe something has gone wrong, maybe I have slipped through the gap, maybe I have not received the appointment, maybe they have not received the referral from the consultant (Interview 4: line 604-610).

(need for letter/notification) Just to let people now they haven't been forgotten (Interview 4: 676-675).

Just left... I am just left waiting... (Interview 6: line 500-501)



# **APPENDIX IX**

Notes for Contributors

## **APPENDIX X**

Copies of Letters of Approval from Ethical Committees